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

# The Exception Needs Care Coordinator in the Oregon Health Plan

February 2000

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# THE EXCEPTIONAL NEEDS CARE COORDINATOR IN THE OREGON HEALTH PLAN

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# EXECUTIVE SUMMARY

Oregon designed several consumer protections for the SSI population and other aged and disabled beneficiaries in Medicaid managed care under the State's 1115 waiver. The **Exceptional Needs Care Coordinator** (ENCC), a type of specialized case manager at the managed care plans, is a cornerstone of these consumer protections. The ENCC and other features of the Oregon Health Plan can effectively assist SSI and other aged and disabled beneficiaries in negotiating managed care and act as a counter balance to the inherent incentive to reduce services associated with managed care. States considering a similar program should look carefully at the lessons learned in Oregon about successes and limitations of Oregon's program design and implementation.

Other consumer protections for aged and disabled beneficiaries in the Oregon Health Plan include:

- Exemptions permitted from managed care for such reasons as continuity of care;
- Liberal plan switching policies;
- A State Ombudsman program;
- Grievance and hearing procedures at the state level;
- The Continuity of Care Referral (CCR) used by case workers to communicate important information about beneficiaries to ENCC or to request ENCC services; and
- Use of the term "medically appropriate" as a more inclusive term to guide coverage decisions than the traditional "medically necessary."

ENCCs are employees of the health plans charged with assisting aged and disabled beneficiaries navigate managed care. The State provides additional capitation payments (averaging about $6 per member per month) to the plans to implement this role. State regulations charge ENCC staff with:

- Early identification of those aged, blind or disabled OMAP members that have disabilities or complex medical needs;
- Assistance to ensure timely access to providers and capitated services;
- Coordination with providers to ensure consideration is give to unique needs in treatment planning;
- Assistance to providers with coordination of capitated services and discharge planning; and
- Aid with coordinating community support and social service systems linkage with medical care systems as necessary and appropriate.

The ENCC program has had a positive impact in Oregon, and has led to creative and flexible service plans for some beneficiaries. ENCC staff also serve as the point of

contact in each plan for the Ombudsman's Office, which receives about 5000 calls a year regarding services to aged and disabled Medicaid beneficiaries. However, ENCC effectiveness is limited by several factors. As found in several consumer and provider surveys, beneficiary focus groups and key informant interviews, consumers and providers alike have very limited awareness of the ENCC program and other protections. As a result, the protections may be severely underutilized. In addition, the latitude the State afforded to plans as they implemented the ENCC program led to variation in the philosophy, staffing approaches, case finding, and ENCC practices at each plan. While some ENCC programs engage in creative case management, flexible service planning and active liaison with community agencies, others appear indistinguishable from traditional managed care member services and utilization review departments.

Oregon designed the ENCC role to provide an additional form of case management in addition to their existing home and community-based services and long-term care case management system. There are formal links between this case management system and the ENCCs to promote integrated care across the acute and long-term care systems. These agency case workers provide plan choice counseling and enrollment and have the authority to exempt individuals from managed care enrollment. They are also intended to serve as advocates on behalf of the aged and disabled in managed care, referring clients to ENCCs for assistance. However, most of the aged and disabled beneficiaries are not in the long-term care system, and do not have the same level of support or advocacy in dealing with managed care issues. For these beneficiaries, the ENCC may be the only potential advocate.

## Recommendations

States implementing managed care for the SSI population would do well to incorporate a similar set of consumer protections as those designed by Oregon. Specialized health plan staff, such as Oregon's ENCCs, are a practical and effective way to assist the aged and disabled in managed care. However, to maximize effectiveness, states need to devise ways to increase utilization of these protections and to ensure that additional payments for specialized case management are used as intended. Contract language should include a clear set of expectations, including acceptable staffing models, expected ENCC activities, and standardized record keeping and reporting requirements.

To increase awareness of the ENCC and other consumer protections, states need to provide ongoing training for staff at collaborating agencies, advocacy groups, beneficiaries and providers. Training activities should be ongoing, in part due to staff turnover at these agencies. Involvement of advocacy groups to help design and publicize the program is also important since some persons with disabilities or chronic health problems are unable to advocate on their own behalf.

# THE ENCC ROLE IN CONTEXT

## Introduction

As a fundamental component of its statewide managed care program, the state of Oregon developed an innovative care coordination role to assist its aged and disabled beneficiaries in the transition to managed care services. The Exceptional Needs Care Coordinator (ENCC), piloted in Oregon, is a specialized case management function housed in managed care plans. The ENCC role is intended to assist aged and disabled Medicaid beneficiaries obtain needed services and to coordinate care within the health plans and with other service systems.[1] This role was also designed assist these beneficiaries obtain special equipment, community services and non-plan benefits that may be important components of their overall health care. The state funds the ENCC role through additional capitation payments averaging $6.02 per member per month to all participating managed care plans. Total expenditures for ENCC services in contract year 1998-1999 were $3,730,563, representing payments to 13 plans for 51,013 beneficiaries. Table 1 reports the additional per member per month payments by eligibility category for the 1998-1999 contract year.

**TABLE 1: Per Member Per Month Payments for ENCC Services by Eligibility Category**

| Eligibility Category | Per Member Per Month Payment for ENCC Services |
|---|---|
| Blind and Disabled with Medicare | $6.37 |
| Blind and Disabled without Medicare | $6.49 |
| Elderly with Medicare | $5.05 |
| Elderly, Part B Medicare coverage only | $6.70 |
| Elderly with no Medicare coverage | $5.00 |

Variation in plan size and enrollment distribution across categories results in a wide range of total annual payments for ENCC services. The smallest plan received annual ENCC payments of $26,700 for its 369 aged and disabled enrollees, while the largest plan received $969,056 for its 13,266 aged and disabled enrollees The mean annual payments to plans for ENCC services was $286,966; the median payment was $179,943.[2]

## Why the ENCC Role in Oregon is Important

Oregon was one of the first states to make the transition to managed care for its aged and disabled beneficiaries, and was the first to require health plans to develop a care coordinator role to assist this population in their transition to managed care. In

[1] The ENCC is also available to children in foster care. However, this experience of this group with the ENCC role is not examined in this report. SSI beneficiaries represent the majority of the aged and disabled enrollees in OHP. Medically needy and some other individuals who use long-term care services are also included.

[2] Figures calculated by Maureen King at OMAP

place since February, 1995, Oregon has now had several years' experience with both managed care and with care coordination activities. The implementation of this managed care feature has drawn widespread attention from state policy makers and researchers who have viewed the ENCC role in Oregon as a potential case management tool to support managed care implementation. Considering its potential value as a success factor for other states, it is important to examine how Oregon has developed the ENCC role. An examination of how this role functions in Oregon and its potential limitations will provide valuable lessons to state policy makers who may be considering a similar program.

This report describes how the state of Oregon designed and implemented its ENCC function, assesses the extent to which this role is meeting the State's objectives, and discusses design elements that support the State's objectives. In order to provide a background for the discussion, we first describe the context in which the ENCC program operates, including the Oregon Health Plan (OHP) and the long term care community case management system. We then discuss the state legislative background and objectives for the ENCC role. This is followed by an examination of how health plans implemented the ENCC role, focusing specifically on how the flexible program requirements led to significant variation in ENCC functions across plans. We also describe the state's approach to monitoring the services. The report concludes with a discussion of the lessons learned from the Oregon ENCC design and implementation that might be of interest to other state policy makers. The appendices include a copy of the Continuity of Care Referral Form, and information about the Ombudsman program.

## Data Sources

The information in this report is a synthesis of extensive case study and survey analyses spanning 1997-1999, as part of a HCFA and ASPE funded evaluation of the Oregon Health Plan. The case studies include several week long site visits during which we interviewed Oregon State administrators, local agency personnel in both urban and rural areas of the state, health plan administrators and staff, providers, and advocates about the ENCC and other aspects of the Oregon Health Plan.

The report also includes findings from several surveys conducted by Oregon as part of its own evaluation activities, and by HER as part of the HCFA and ASPE funded evaluation. Two mailed beneficiary surveys were conducted by the State of Oregon in collaboration with Oregon Health Services University, one of adults and one of parents of children with special health care needs. HER, in collaboration with Research Triangle Institute (RTI), conducted a telephone survey of over 3000 disabled (children and adults) and elderly Medicaid beneficiaries. We also conducted mailed surveys of physicians and agency providers (home health agencies, rehabilitation agencies, and community mental health providers). Other sources include review of Oregon legislation, administrative rules, and reports generated by the State, including OMAP's own evaluation of ENCC implementation.

We talked directly with consumers in a series of eight beneficiary focus groups held in July of 1998. These focus groups brought together persons with similar disabilities or health status to discuss their experience in OHP. Two groups were comprised of participants with physical disabilities, two with developmental disabilities, two with chronic mental illness, and two groups of community-residing persons age 65 or older. Fifty-eight people participated.

## The Oregon Health Plan

### *Overview*

The Oregon Health Plan, a statewide Medicaid reform program, was implemented in two phases, beginning in 1994. Phase I extended Medicaid eligibility to uninsured residents with incomes up to 100 percent of the Federal Poverty Level, while mandating enrollment in managed care for the TANF, SOBRA, General Assistance, and expansion populations. Phase II, implemented in February, 1995, moved SSI recipients, other aged and disabled beneficiaries, and foster children into managed care. Medicare/Medicaid dual eligibles are included, but are exempted from Medicaid managed care if they are enrolled in a Medicare plan that does not have a Medicaid contract or if they have supplemental insurance or other third party resources. Beneficiaries may be exempted from managed care enrollment on a case by case basis for reasons such as continuity of care. The State's goal is to enroll as much of the Medicaid population in managed care as possible, with enrollment in fully capitated health plans wherever possible and primary care case managers (PCCMs) as an alternative. In December, 1998, 65. % of Medicare/Medicaid dual eligible beneficiaries were enrolled in OHP plans, and 77.5% of the aged and disabled population without Medicare coverage were enrolled in OHP plans.[3] Using annual enrollment figures, the percent of Phase II beneficiaries ever enrolled in managed care is a little higher.

ENCC services discussed in this report were designed to assist the Phase II enrollees in Medicaid managed care. While the Phase II enrollees are predominantly SSI beneficiaries, we refer to the target population throughout this report as aged and disabled beneficiaries to acknowledge the State's inclusion of individuals who receive Medicaid but are not SSI beneficiaries.

### *OHP Benefit Package*

The Oregon Health Plan includes physical, mental and dental health services delivered through managed care organizations. The State's extensive home and

[3] This figure is a point in time percentage for December 1998, taken from the December 1994 *Enrollment and Disenrollment Report*. For more information about enrollment including tables with counts by enrollee group, see "Enrolling Elderly and Disabled Beneficiaries in Medicaid Managed Care: Lessons Learned from the OHP." The majority of those not enrolled in Medicaid managed care are exempt due to third party resources, including Medigap policies, commercial insurance, or membership in a Medicare managed care plan that does not have a companion OHP.

community-based services, and institutional long-term care services are delivered on a fee for service basis administered separately by the Senior and Disabled Services Division (SDSD). OHP utilizes a benefit package defined by a prioritized list of health care services, delivered on a capitated basis. The State offers a generous service package including physical, dental, mental health, preventive, inpatient and outpatient, rehabilitation, ancillary, and home health services and durable medical equipment (DME). While the capitation payments assume that plans only deliver services covered above a designated line on the priority list, plans sometimes choose to provide additional services either on a case by case basis or across the board in order to enhance quality of care.

Physical health and substance abuse services are provided by fully capitated health plans (FCHPs). A few FCHPs also provide mental health services under separate capitation, but most mental health services are delivered through separately capitated Mental Health Organizations. Dental services are provided through separately capitated Dental Care Organizations. A small percentage of beneficiaries receive their physical health services through Primary Care Case Management.

Although they receive their long-term care services through the SDSD system, most nursing home residents and recipients of home and community-based services (such as personal care) are enrolled in managed care organizations for their medical care. The plans are also responsible for 20 days of skilled nursing facility care as a post-acute service, and Medicaid home health services (nursing, home health aides and rehabilitation services). Aspects of the SDSD administered system and the interaction between these local agency caseworkers and ENCCs are described later in this report. A more detailed description and discussion of the interaction of OHP and Oregon's long-term care system will be described in a future HER report.

## Oregon's Other Special Provisions for the Aged and Disabled in Managed Care

The ENCC role was implemented along with several other important measures intended to make managed care work for aged and disabled beneficiaries. In this context, the ENCC program was intended to build on features of OHP and to function collaboratively with consumer protections for the aged and disabled population. These special provisions include:

> *Special enrollment process:* Oregon deliberately instituted a separate enrollment process for the aged and disabled from that of its other Medicaid beneficiaries. Aged and disabled beneficiaries are primarily enrolled through face to face enrollment counseling. The enrollment process is handled by the local agencies responsible for either aging services or disability services (in some cases, one agency is responsible for both groups). Homebound beneficiaries receive enrollment counseling in their homes.

*Liberal exemption policies and disenrollment policies:* The aged and beneficiaries in Oregon can be exempted from managed care enrollment for several reasons. Most important to this population, exemptions can be granted for individuals who have existing relations with providers who do not participate in managed care, or whose existing set of providers are not within a single managed care plan's provider network. The purpose is to prevent disruptions in care and to protect ongoing physician- patient relationships. Disabled and elderly beneficiaries may also switch plans with local caseworker approval at any time for cause. In contrast, other traditional Medicaid population enrollees must seek approval for plan switches from a central, state level office.

*Ombudsman's Office:* Aged and disabled beneficiaries, as well as all other Medicaid beneficiaries, have access to a state Ombudsman to address grievance and hearing procedures. Each beneficiary has an enrollment card labeled with the 800 number of the Ombudsman. The Ombudsman also has direct contact with the ENCCs and works collaboratively with ENCCs to review and refer cases.

*Medical appropriateness:* The State substituted the term "medically appropriate" for "medically necessary" to communicate a wider coverage intention. Where medical necessity is often interpreted as restricting coverage to lifesaving or cure-oriented interventions, medically appropriate would (at least theoretically) include interventions that would sustain function or prevent complications or decline. The priority list (the main mechanism for determining benefits under OHP) was also expanded to include conditions associated with chronic illness and disability.

## Interaction with Oregon's Local Case Management Systems

### *Senior and Disabled Services Division*

The ENCC function was implemented as an addition and complement to the existing county-based case management system. This system, which includes both Senior and Disabled Services Division (SDSD) offices and Area Agencies on Aging (acting under the direction of SDSD), administers Medicaid eligibility and long-term care services. The services the local agencies administer include home and community-based waiver services (e.g., personal care assistance), and preadmission screening for nursing facility and other forms of residential care (assisted living, adult foster care, and residential care facilities). Throughout this report we refer to the case workers in the SDSD administered system as "local agency case workers."

Medicaid home health services (nursing, home health aides, and rehabilitation therapies) used to be under the control of the SDSD and AAA offices, authorized by the local agency case workers responsible for long-term care services. The local agency case workers continue to authorize these services for individuals exempted from managed care enrollment. These local agency case workers also continue to assist these beneficiaries find providers who accept Medicaid.

Under OHP, these local agency caseworkers assumed new roles in relation to managed care. They provide managed care plan choice counseling and enrollment, determine exemptions from managed care, and approve and process plan disenrollments and plan switching. Oregon incorporated these duties into the existing local agency system in acknowledgment of these caseworkers' knowledge, experience and orientation to advocacy for the aged and disabled. They are able to provide valuable information to the health plans about individual beneficiaries and their long-term care service plans, and about available community services. These case workers also direct their clients to ENCCs and to the State Ombudsman to resolve problems with the plans, and advocate directly with ENCCs on their clients' behalf.[4] ENCCs and local agency caseworkers are expected to communicate and collaborate as needed.

To foster this communication and to provide the ENCCs with valuable information known to the local caseworkers, Oregon developed a formal communication tool, the Continuity of Care Referral form (CCR). The CCR and its use are discussed in more detail later in this report. Figure 1 summarizes the local agency case worker activities for aged and disabled beneficiaries.

## Other Community Agencies

Aged or disabled Medicaid beneficiaries may also receive services and case management from additional state systems. These systems include Services to Children and Families, Mental Health and Developmental Services Division, and others. The state intended the ENCC program to serve as a junction between health plans and these various agencies, enabling patients to take advantage of the resource base of community case workers, while providing case workers and enrollees with a contact at the health plans.

[4] In practice, the advocacy role of the caseworkers varies with their level of involvement with their clients. Caseworkers serving clients who receive institutional or home and community based long-term care services (about one third of the aged and disabled) maintain ongoing contact with their clients as they perform assessments, develop service plans, and authorize and monitor these services. These caseworkers carry caseloads of 69 community residing long-term care cases or 130 nursing facility residents, and their clients are likely to consider these caseworkers as a resource for a range of problems, including problems with their health plans. In contrast, two thirds of the aged and disabled population are served by workers whose functions are limited to eligibility determinations and OHP enrollment functions. These workers carry 225 - 402 cases each (depending on whether the clients also receive food stamps). Focus group participants who were served by these “financial” workers did not think of their worker as an advocate or resource regarding problems with their health plans.

| FIGURE 1: Role of SDSD Case Workers | |
|---|---|
| **For Managed Care Enrollees** | **For Beneficiaries Exempted From Managed Care** |
| Determine Medicaid eligibility.<br><br>Assess long-term care needs and authorize home and community-based waiver services and long-term care facility placement.<br><br>Direct problems to the Ombudsman.<br><br>OHP plan choice counseling.<br><br>Process managed care enrollments. Approve plan disenrollment or switching.<br><br>Coordinate with ENCC at managed care plans. | Determine Medicaid eligibility.<br><br>Assess long-term care needs and authorize home and community-based services and long-term care facility placement.<br><br>Direct problems to the Ombudsman.<br><br>OHP plan choice counseling.<br><br>Approve and process managed care exemption.<br><br>Work with individual medical providers to assist beneficiaries access care.<br><br>Authorize Medicaid home health services. |

# THE ENCC ROLE AS ENVISIONED BY THE STATE

The State of Oregon conceived of the ENCC role as a creative approach to case management. It encouraged plans to "think outside of the box" of traditional medical case management: to look at the social as well as medical needs of the individual.[5] This section describes the legislative and administrative foundation of the ENCC role, and how the State used this foundation to develop the ENCC function as an important managed care feature for the aged and disabled.

## Legislative Background and History

The ENCC role had its origin in a coalition building process, during which OMAP, SDSD and other agency stakeholders and advocates developed the concept through a collaborative process. The ENCC concept is codified in legislation in Senate Bill 530, the implementing legislation for the Oregon Health Plan, that includes several consumer protections intended to safeguard this population and respond to their complex needs. Among these protections was one calling for: "Case management services in each health care provider organization for those eligible persons who are aged and described in ORS chapter 413 or who are blind or disabled and described in ORS chapter 412." According to the statute, these case managers "shall be trained in and shall exhibit skills in communication with and sensitivity to the unique health care needs of people who are elderly and those with disabilities."[6]

## Role as Articulated by Administrative Rule

The general role of the ENCC was further defined in Oregon administrative rules.[7] The current definition of the ENCC role as articulated in Oregon Administrative Rules (OAR) has been integrated into managed care plan contracts with OHP. The OAR defines the ENCC role as "specialized case management service provided by Fully Capitated Health plans to OMAP members who are Aged, Blind, Disabled" consistent with OAR 410-1410405.[8] Oregon Health Plan Prepaid Health Plan Exceptional Needs Care Coordination (ENCC) *duties include but are not limited to:*

- Early identification of those Aged, Blind or Disabled OMAP members that have disabilities or complex medical needs;
- Assistance to ensure timely access to providers and capitated services;

[5] Statewide Report: Evaluation of Exceptional Needs Care Coordination Program. OMAP, 1998.

[6] Senate Bill 5530. 67th Oregon Legislative Assembly. 1993 Regular Session. Section 18, subsection 2.

[7] All OAR references are to OAR 410-141-405 which pertains to the ENCC program under the OHP.

[8] OAR 1998 Compilation, Department of Human Resources, Office of Medical Assistance Programs, 410-141-000, #36.

- Coordination with providers to ensure consideration is given to unique needs in treatment planning;
- Assistance to providers with coordination of capitated services and discharge planning and;
- Aid with coordinating community support and social service systems linkage with medical care systems, as necessary and appropriate.

## Basic Expectations of the ENCC Role

The programmatic goals and administrative regulations provide broad requirements for the ENCC, but they include few prescriptive rules for implementing the role. Oregon Administrative Rules[9] lists ENCC requirements but these are lacking in detail. For example, plans must have a job description on file, but staffing ratios are not dictated and qualifications for ENCCs are suggested but not specified. These regulations were incorporated into the State's contracts with the health plans. Consistent with Oregon's desire to allow plans latitude in designing their programs, the contracts identify what the state wanted, but not how the plan should accomplish the mandated task.

Contract language specifies the following requirements:

- ENCC services available during regular business hours at the request of members, representatives, physicians, health care provider, or agency case managers.

- Dedicated personnel and documented description of the program. Staff ratios not dictated but job qualifications are suggested.

- Respond to requests within one working day.

- Create and maintain an ENCC record on each member in need of ENCC services.

- Meet the requirements such as training in and ability to communicate with and be sensitive to the needs of members.

- Inform plan practitioners of the program, and have procedures for responding to requests and documenting ENCC services.

This list of requirements may appear prescriptive, but in actuality, allows each plan to develop its program individually. There are few statewide standards for reporting or program design. For example, there is no standard about what constitutes acceptable availability. The State believed that this flexible design would allow health plans to

[9] OAR

develop innovative programs. In addition, since Oregon, like most states, had no experience providing managed care to aged and disabled beneficiaries, they had little experience to use as a foundation for more specific program requirements.

While contracts with health plans do not explicitly describe the ENCC role, the state has some basic expectations of the ENCC function. At a minimum, the state expects ENCCs to collaborate with state agencies and to focus their program on elderly and disabled OHP members. As the primary point of contact within health plans for the aged and disabled, the ENCC should solve problems that arise in coordinating care.

A training manual issued by the State describes, in general terms, expected ENCC activities. These expectations include:

- Explain the use of managed care, such as using networks, explanation of denial and referral, gatekeeping process, the need for referral to specialists, and appropriate use of hospital emergency rooms.

- Approve or advocate with the Medical Director for particular services based on medical appropriateness that may not be spelled out under covered services. In some cases this may include covering usually unfunded services because of comorbidities or the risk of complications related to underlying disabilities or chronic conditions.

- Link members to alternative and community resources such as charitable organizations and others located outside of the health plan, including the state long term care system.

- Coordinate care among providers in network; provide creative case management specific to needs of disabled and elderly.[10]

## The Decision to Place the ENCC Within the Health Plans

Policy makers and advocates debated whether ENCCs should be located in or outside of health plans. Advocates were concerned about the objectivity of ENCCs as plan employees, and that the financial incentives of these plans may influence their design of the ENCC role, steering it more towards cost containment than service coordination. For that reason some supported an independent ENCC outside of health plans. However, the state saw the greatest advantage in housing the ENCC role within health plans, primarily to provide a direct connection between the ENCC, health plan management, and health care provider networks. In addition, this arrangement offered

[10] The Oregon Health Plan Medicaid Demonstration, Aged and Disabled Training Resource Book, 11/1/94.

the advantage of providing the Ombudsman's office with a distinct contact person within the health plans. From a consumer perspective, this arrangement could provide an advocate within health plans, to assist them in navigating the often complex networks in managed care plans. How this decision actually played out in Oregon is discussed in later sections.

# THE ENCC ROLE AS IMPLEMENTED

## Overview

As a result of the broad flexibility of the legislative guidelines for the ENCC role, managed care plans developed the ENCC role in a variety of ways. This variation is a logical result of the flexibility afforded by the state and led to a useful learning laboratory, providing specific design elements that other states might want to replicate or avoid. In this section, we describe design elements developed by the plans including organization and staffing models and case management orientation. We also evaluate those design elements in relation to the State's intended objectives.

## Organization and Staffing Models

Given broad discretion to design their ENCC roles, health plans faced several key decisions about where to locate this role within the organization, the amount of decision making authority to grant ENCCs, and what qualifications and background to seek in hiring ENCCs. The choices plans made in these areas correspond roughly with plan size and previous level of case management experience.

### *Organizational Structures*

Larger plans generally locate the ENCC role in an existing department where the role is delegated to a number of people. While the state discouraged delegating the role across departments or staff, such arrangements were not prohibited. In this case, the ENCC role may not be directly associated with one person, but is instead comprised of a team under the direction of a health plan administrator, often the medical director. Team approaches per se, are not inconsistent with the ENCC goals, but there are impacts associated with the type of department (e.g. utilization review vs case management) in which the ENCC function is located, as we discuss in an upcoming section.

In addition, entree to the ENCC staff can be direct or channeled through member services. Some plans include direct numbers to ENCC staff in brochures and member handbooks. Other plans only provide information about accessing member services and expect member services staff to determine when a call should be referred on. While using member services as the first line of communication appears efficient organizationally, it may undermine the state's objective to ensure that aged and disabled beneficiaries receive the intended level of support. Expectations of ENCCs greatly exceed the usual member services role. ENCCs are expected to understand the varied service needs of people with chronic illness or disability, communicate effectively with aged and disabled beneficiaries, understand the details of the OHP benefit

package and of other service systems serving these beneficiaries, and develop creative approaches to meeting beneficiary needs.

For this model to work, member services staff need to identify beneficiaries eligible for ENCC services and correctly identify situations that warrant ENCC intervention. Focus group participants with physical disabilities (few of whom were aware of ENCC services) reported important gaps in knowledge on the part of member services staff with whom they had spoken. Medicare/Medicaid dual eligibles enrolled in plans that covered both their Medicare and Medicaid benefits reported that member services staff did not understand the provisions of the two systems. For example, member services staff had limited understanding of the coverage provided for services such as durable medical equipment. Enrollees who spoke with member services were told that services were not covered based on only one or the other benefit package (e.g., whether equipment is available through rental versus purchase). One beneficiary stated "the plans are either not aware that you are dual eligible or they forget there's a difference in coverage." According to these beneficiaries, member services staff also misinterpret the concept of Medicare coverage being primary to mean that only Medicare coverage applies to dual eligible beneficiaries.

Although these beneficiaries described problems that would have warranted ENCC intervention, they were not referred to other plan staff by member services. Since some calls will originate in member services even in plans that provide direct access to a distinct ENCC department, member services staff in all plans need training regarding "ENCC appropriate" calls.

In contrast to organizations that delegate ENCC activities across several departments and staff members, some plans use a more focused, hands-on approach to filling the ENCC role. In these plans, a case manager's sole responsibility is to function as an ENCC, working directly with beneficiaries to coordinate care. In a small plan, the ENCC might handle the range of coordination needs. In a larger plan, distinct ENCC staff may perform a sort of triage, handling some issues and referring those with complex medical needs to the medical case management department. In these plans the role of the ENCC is not subsumed into several departments and is more readily identifiable to beneficiaries. Beneficiaries who find their way to these ENCC staff have the type of distinct point of contact the state intended. Education and training efforts on the part of the State or the plans can be targeted to a smaller group.

### *Range of ENCC Authority*

The plans also vary in the level of autonomy ENCCs have to make important medical decisions. The range of authority includes:

- Requiring ENCC staff to consult with the medical director prior to authorizing any services;
- Independent authority to authorize specific services such as medical supplies and durable medical equipment; or

- Broad latitude to make decisions on behalf of disabled and elderly members.

ENCCs may also influence plan policy on a system-wide basis if they are included on standing committees. ENCCs in some plans participate in specific committees such as: the utilization review committee, which has significant influence over decisions regarding provision of below-the-line services;[11] and the quality improvement committee, enabling the ENCC to shape plan policies that directly impact the quality of care received by elderly and disabled enrollees.

### *Physical Location of the ENCC: Local Versus Remote*

According to OMAP, each plan must have one person who is centrally responsible for the ENCC function, although the duties are often spread across a number of workers. Some health plans place the ENCCs in a local health plan office to coordinate services for individual counties; others house the ENCC function in the plan's administrative offices which are often a significant distance from many local service areas. For example, one health plan with administrative offices in a metropolitan area also enrolled members in other counties across the state. In this plan, ENCCs operated from the central office. Some advocates and local agency caseworkers found these "remote" ENCCs were more difficult to reach than local ones, and often lacked vital knowledge of the local community services necessary to successfully fulfill the responsibilities of the ENCC role.

### *Staffing: Who Works as an ENCC?*

In keeping with its objectives of program flexibility and local innovation, Oregon did not specify particular personnel qualifications for ENCCs. OAR simply requires that candidates be "trained in and exhibit skills in communication with and sensitivity to the unique health care needs of the aged, blind and disabled." As a result, the training and background of ENCCs varied across plans, with plans choosing utilization review nurses, medical case managers, nurses with previous experience in community service systems, and/or social workers to fulfill the role.

Despite the regulatory requirements, consumers and advocates we interviewed repeatedly commented on the variation in ENCC knowledge of the medical and social needs of the disabled and elderly and of available community resources. This variation exists both within and across plans. Consumers and advocates also commented on turnover in ENCC staff as frequent and problematic.

The approach to staffing, like other features, appears to vary with plan size. Smaller plans generally emphasize knowledge of the local community services in their employment decisions more than formal training and are likely to have either social

[11] Below-the-line services are medical services which are clearly excluded from the benefit package and not included in the capitation payments to the health plans. The OHP benefit package is based on a prioritized list of services, and the State only funds services above a specified cut-off line.

workers or registered nurses in the role. Larger plans appeared more likely to use a team approach, sometimes a combination of social workers and registered nurses, or spread the duties across member services staff and nurses in the utilization review department. The background of the ENCC staff appears to influence ENCC functions across plans. For instance in certain plans, nurses focus more on high cost case management and utilization review issues, while ENCCs with social work backgrounds or stronger community resource ties focus on social and community resource needs. Plans that utilize both social workers and nurses triage medically complex cases to nurses and have social workers handle other types of problems or questions. One ENCC supervisor at a large plan told us it was important to include a social worker on the team, or to have nurses who can "think like social workers" extending beyond a narrow medical model orientation.

### *Caseload Levels for ENCCs*

Contracts and administrative rules do not establish staffing requirements for plans or any means to determine if staffing is adequate. The only requirements are for a person responsible for the program at each plan, and for each plan to have at least one full time equivalent (FTE) dedicated to the ENCC program. Caseload levels vary by plan and region across the ENCC programs in Oregon, and clearly caseload size cannot be described in plans that absorb the ENCC role within existing structures and positions.

Plans reported varying approaches to counting cases and measuring caseloads and some could not quantify their caseloads. One plan reported that its ENCC staff maintain a huge log of calls, but that each ENCC handles 25 active cases at any given time, while another plan's ENCC reports an active caseload of 80 to 100. Each of these plans use growth in the caseload, as they define it, to inform their staffing decisions. In some plans with a stronger utilization review focus, the ENCC function is absorbed within that department, making no distinctions between case management services provided to aged and disabled members, and those provided to other OHP members and commercial members. Information about the ratio of disabled and elderly plan members per ENCC for plans taking this approach were not generally available. However, one of the largest plans participating in OHP has approximately one ENCC for every 2,400 elderly and disabled OHP enrollees. They contrast this ratio to their medical case management staffing ratios of 1:11,000 -12,000 Medicare members, and 1:40,000 - 50,000 commercial members.

Oregon is trying to determine how to evaluate the ENCC staffing ratios and patterns. There are several component issues. Is there an ideal number of FTEs at a plan? How does that relate to plan size? In what ways may it be desirable to spread the role across a number of plan staff? Larger plans may have fewer FTEs relative to the membership, but may have a larger absolute number of ENCC staff available at any given time. Advocates and local agency case workers strongly recommend clearly identified staff who serve only as ENCCs or have a limited set of additional duties. Advocates, local agency case workers, and State administrators all prefer models where ENCC staff are separate from the utilization review department.

There is no clear evidence by which to define optimal caseload size or the appropriate ratio of ENCC FTE's to members. In addition, as we detail later in this report, consumer and provider awareness of the ENCC feature is low. Therefore, staffing ratios that may be adequate now, may not be adequate as the program becomes more widely known and accessed.

## Differing Orientation Across Plans

ENCC services cover a broad range of activities including: educating enrollees about the benefits and limits of the health plan, care coordination, health service authorization, development of creative care plans, facilitating referrals within the plan, granting exceptions to the defined plan benefit package, and linking enrollees to services outside the plan. Plans demonstrated many diverse approaches to providing ENCC services and differed in which of these services ENCCs provide or emphasize. While state representatives were careful to assert that no two programs were alike, the plans we interviewed fell somewhere on a continuum from plans focusing primarily on utilization review, to those with a more flexible and person centered approach to care coordination and service authorization.

### *Utilization Review Orientation*

A health plan's previous utilization review or high cost case management experience prior to participation in OHP appears to strongly influence its approach to the ENCC role. Such plans tend to integrate the ENCC role into their existing system, and appear to extend their utilization review orientation to the ENCC function. This approach seems the least consistent with Oregon's objectives. OMAP is particularly concerned about whether staff functioning both as ENCCs and in a utilization review capacity can separate their responsibilities and perform the ENCC function as intended.

Example

A plan with a strong insurance company background integrated the ENCC function as an extension of their traditional utilization review system. The same staff serve both as ENCCs and to monitor high-cost utilization for the entire plan membership. The primary function of the ENCC role at this plan is to enforce the plan's benefit package. In other words, they "manage tightly to the line," using the prioritized list as their guide in authorizing services. Services not clearly covered by OHP are deemed to be outside the plan's purview. Indeed, one utilization review supervisor described some of the calls received in his department to be burdensome, outside the realm of the department's experience and orientation, and not requiring the clinical expertise of his staff.

### *Flexible Case Management Orientation*

Other plans take a much less restrictive approach. Such plans do not limit access only to those services explicitly covered by OHP, and have developed individualized and creative care planning approaches. The interventions described by these plans are clearly consistent with the state's goals. However, if all their case finding is based on the type of high cost case identification the plan performs routinely, or as part of hospital discharge planning activities, then additional capitation payments for ENCC services would appear to be unjustified.

Example

ENCC staff in one large plan created individualized pediatric care notebooks for parents and extensive case management support for chronically ill or disabled children with high medical costs. This intervention ultimately saved the plan an estimated $18,000 per case in annual acute care costs. These individualized notebooks detailed daily care needs in the parents' native language and at the parents' reading level, using illustrations of pills and syringe markings and medication schedules to assist parents with providing medications as prescribed. The parents bring these notebooks with them to all of their child's medical appointments, where the notebooks serve as shared records across providers and can be revised as needed. In addition to these notebooks, the plan provided information to the emergency room used by each family. This information includes important medical information, and contact names and numbers for the primary care and other providers, ENCC, agency case workers, and informal supports. Through this comprehensive set of interventions, clearly an example of well coordinated care, the plan improved the health status of the children and achieved substantial savings. In addition, parents (including some with developmental disabilities themselves) were pleased with their increased ability to succeed in caring for their children.

These cases were identified by their high acute care utilization. In contrast to plans embracing strict utilization review approaches, plans taking this approach are delivering the kind of flexible intervention that the State had intended for the aged and disabled population. The question remains, however, whether the intervention can be attributed to the ENCC role, or reflects the type of creative care planning performed traditionally by this medical case management department for high cost cases.

### *Patient Advocacy Orientation in Smaller Plans*

Smaller plans with little or no prior experience with utilization review or high-cost case management generally demonstrate an individual-focused approach to their ENCC functions. In such plans, ENCCs focus on the needs of enrollees on a patient by patient basis, often directly fielding and responding to calls from enrollees rather than receiving only those calls passed on by the general member services department or identified through utilization review activities.

## Examples

The ENCC in a smaller plan authorized homemaker and home health aide services to a single parent family with two special needs children.[12] The type and amount of services were beyond the plan's interpretation of the mandated benefit, but were necessary to support the parent in keeping the children at home.

Another plan that treats a predominantly rural population set up a walk-in ENCC office; plan members are encouraged to drop by if they have any problems. This street-level accessibility highlights the plan's flexible approach to providing ENCC services, in contrast to the stricter utilization review approach of other plans.

In Figure 2 we summarize approaches we observed which best support the State's objectives for the ENCC program.

**FIGURE 2: Best Practice Design Features**

| Design Feature | Advantages |
|---|---|
| Specified ENCC staff, directly available to members and other callers | Provides a clear point of contact for beneficiaries, providers and collaborating agencies.<br>Bypasses member services staff who are not prepared to deal with the range of issues that face aged and disabled beneficiaries.<br>State and plans can target staff training and evaluation. |
| Separate from utilization review department | The desired approach to flexible case management is different from traditional utilization review activities. |
| Social work participation | Enhances ability to resolve a wide range of problems. |
| Team approach with medical case management staff | Referral to medical case management appropriate when beneficiaries have complex medical needs. |
| Local staff | Local staff are better able to learn about community resources and establish effective relationships with local providers and agency case workers. |
| Participation in policy making committees within plans | Able to work toward systematic change in managed care plan operations. |
| Authority to authorize frequently needed services or supplies | Facilities timely authorization and efficient plan operations. |

[12] Children are not included in Oregon's home and community-based waiver, so the plan could not refer this case to SDSD for inhome services.

## ENCC Activities and Interventions

### *Case Finding*

As we have discussed, some potential ENCC cases are found through utilization review activities. However, ENCC involvement is more commonly triggered through direct calls to ENCC staff and through review of the Continuity of Care Referral Forms submitted by the local agency case workers.

### *Continuity of Care Referral Form*

OMAP developed the Continuity of Care Referral Form (CCR) as a mechanism by which the local agency caseworkers in the SDSD system would provide important information about their aged and disabled clients to the ENCCs, and to identify individuals who might be in need of ENCC services. Local caseworkers may complete these forms during plan enrollment, when enrollees change plans, or as needed to request ENCC services for a client. A copy of the recently revised form is attached as an appendix to this report.

The CCR form can provide ENCCs with information about living arrangements, health status, medical needs, important equipment or supplies (such as oxygen), the name of the local agency case worker and any special concerns that case worker has about meeting the beneficiaries' needs. At the outset of OHP, the form also played an important political role. Many local agency case workers feared that managed care would not meet the needs of their clients. The CCR provided the caseworkers with a means to convey their particular concerns about individual beneficiaries' health care needs, and to initiate communication between the local agency case workers and the ENCC staff.

ENCCs report that information about living arrangements and the ability of the individual to communicate are especially valuable to them. The recently revised CCR also includes information about specific medical conditions (e.g., diabetes and cardiac conditions) at the plans' request, so that ENCCs can flag members with these conditions. However, there is no state requirement for the CCR to be completed for each enrollee or at any specific time. Instead the form is completed at the discretion of the caseworker. ENCCs report varied experience with case workers' use of the CCR form across agencies, workers and over time. Many caseworkers made extensive use of the CCR during the initial enrollment phase, but that use has fallen off. In practice, the form has showed mixed success, as local case workers vary in their use of the CCR and in the completeness of the information they provide. Some aspects of this variation reflect the different philosophies and practices by county. For example, in one area, local agency case workers have refused to complete CCR forms, citing concerns about client confidentiality.

### *Direct Calls to ENCCs*

Initially the CCR forms generated the most ENCC referrals. Currently, ENCCs receive many of their client referrals through direct phone contact from aged and disabled enrollees and their families, local agency case workers, and advocates. Responding to these calls is a major ENCC activity. This direct contact enables the ENCC to work with members who have questions about their coverage, about their plan services, or who need additional resources. In order to facilitate this contact, some plans provide members with a direct phone line to the ENCC department, while others place member service representatives in charge of screening in-coming calls.

ENCCs also receive calls from the State Ombudsman. The Ombudsman received almost 5,000 calls in 1997 from or about aged and disabled beneficiaries. The Ombudsman either directs the caller to the appropriate ENCC or calls the ENCC directly. The majority of the calls to the Ombudsman's office are about billing issues (e.g, bills received for "below the line services" and for emergency room visits, ancillary services, and durable medical equipment when the provider did not have prior approval from the plan). Pharmacy problems, such as formulary restrictions and having to wait the required amount of time to get a refill, are the second most frequent type of problem. About 10 percent of the calls received by the Ombudsman are about access to specialists.

The ENCC department is the point of contact within each plan for the Ombudsman, who expects the ENCC to investigate, address and report back on the issues raised. As a result, the ENCC greatly simplifies the work of the Ombudsman's office. In contrast, the small percentage of aged and disabled beneficiaries who are exempt from managed care, and remain in fee-for-service, require extensive work on the part of the Ombudsman's office. In these cases, the Ombudsman has to work with the Provider Relations Unit at OMAP to investigate why a bill was denied (resulting in the provider billing the beneficiary), call the provider to resolve the problem, and follow up with the beneficiary.

In addition to the State administrative offices and the local agency case workers, other service providers may contact the ENCCs. For example, some case workers at the organizations like the Association for Retarded Citizens (ARC) and United Cerebral Palsy, and resident managers in group homes are aware of ENCCs and contact them on behalf of their shared clients. Physicians, home health agency staff and other providers can also contact ENCCs to discuss problems or request authorization for additional services, but it appears that they rarely do.

### *Systematic Approaches to Case Finding*

There are few systematic approaches to identifying individuals in need of care coordination at the plans. Plans may engage in case finding through their utilization review activities, such as the plan that identified the children with annual acute care costs over $50,000. One plan does screen all new members by sending a mailed

survey and flagging individuals for medical case management. Through its own evaluation processes, that include record reviews, OMAP staff identify patterns of service us that may identify individuals or groups who need ENCC services.

## ENCC Interventions

ENCCs perform a wide range of activities including fairly mundane care coordination and member education activities as well as creative case management activities. The day to day work includes explaining the gate keeping system to beneficiaries, facilitating referrals, resolving billing problems, and providing information and referral to resources outside the plan. ENCCs also collaborate with the local agency case workers on the service plans for individuals with chronic needs for in-home services spanning both Medicaid home health and home and community based waiver services.[13] This collaboration includes authorization of Medicaid home health services as part of an ongoing plan of care or as emergency back up when personal care attendants are not available.

In addition, we heard many examples of creative solutions developed by ENCCs to meet beneficiaries' needs. Many of these interventions exemplify the state's intention for ENCCs to serve as advocates for services that straddle the boundaries between social and medical needs, and to assist beneficiaries in obtaining a wide array of services. In addition to the pediatric notebooks and authorization of homemaker and home health aide services described above, ENCCs, agency caseworkers, and others described the following interventions:

- One residence manager for people with intensive physical needs stated the health plan for her residents initially refused to pay for "Thick-it", a substance used to thicken liquids to prevent aspiration. Since all residents in the facility needed this thickener, the manager consulted an ENCC, who successfully advocated with the health plan to cover the substance.

- A health plan member refused to take blue pills and was therefore noncompliant with her-medication regimen. Her ENCC convinced a local pharmacy to repackage the pills in a white capsule to enable the woman to adhere to her prescribed regimen.

- Several health plans have reported collaborating with dental providers to provide diagnostic procedures for severely disabled clients while these clients are under sedation for dental work.

[13] The boundaries between Medicaid home health, for which the plans are responsible, and home and community-based waiver services, for which the SDSD workers are responsible, are unclear and remain a difficult topic on both the systems level and case by case. We will report in detail on this issue in the future report on the interaction between OHP and the long-term care system.

- One health plan places colored stickers on files that indicate the need for ENCC services to set them apart from other OHP cases. This assists in quickly identifying those enrollees who may warrant ENCC services.

- One ENCC drove out to a patient's house and painted the rocks next to her mailbox white, because medical transport personnel, including emergency medical technicians, could not locate her residence.

- ENCCs have authorized limited telephone service to members otherwise unable to place or receive calls from their physicians or call for emergency medical services.

- An ENCC successfully advocated with outside non-profit organizations to help finance horseback therapy for a plan member. This horseback therapy was clearly outside of the plan benefit package, but was nonetheless considered an important component of care for this particular patient.

- One ENCC successfully arranged for a charitable organization to finance breast reconstruction, a procedure that was not covered by OHP at the time.

- ENCCs at several plans described the use of behavioral contracts to guide the health care use of high-risk clients. These contracts involved such problem areas as overuse of the emergency room, seeking care outside of provider networks, and showing patterns of missed appointments. Contracts are written in the presence of ENCCs, health plan officials, and caseworkers, if applicable. As a punishment for violating contracts, beneficiaries may be formally censured, or even disenrolled from the plan.

## ENCC Training Activities

At the outset of ENCC implementation, OMAP held training sessions and issued a manual to the plans delineating the ENCC role and describing the role of the local agency caseworkers and relevant community agencies. OMAP also holds quarterly regional meetings with round table discussions about ENCC practice issues, which ENCCs are expected to attend. Over time, ENCCs in some parts of the state began to meet together (independent of the State) to discuss their experiences. These luncheon meetings, which have been an important collaborative component of the program, are usually held monthly. ENCCs compare experiences and skills to try to help develop and learn from best practices. Some ENCCs also contact the Ombudsman to discuss individual cases and ask for input.

Despite these efforts, during our site visit in February 1998, advocates reported that there is wide variation in ENCCs awareness of the needs of the disabled and elderly, and of available community resources. Some advocates stated the early training seemed to have been effective, but that due to turnover in ENCC staff at the plans,

there was a need for more ongoing training. According to the advocates, this variation exists not only across plans, but within managed care plans. One consumer reported she had contact with three ENCCs in one year at her health plan, and that only the first was knowledgeable about medical issues related to disability. ENCCs themselves are looking for direction. One ENCC told us she would benefit from written examples of the types of problems she might encounter and appropriate solutions. Case workers in one developmental disabilities services office have invited ENCCs to attend case review meetings to discuss challenging situations. An SDSD administrator has worked extensively to increase understanding and communication between ENCCs and the local agency case workers, but has found this to be a slow going process that would benefit from increased resources from the state.

## Publicizing the ENCC Role

As OMAP stated in a 1999 report, "ENCC is not a household term."[14] Evaluation activities conducted by Oregon and by HER consistently find that only a fraction of the aged and disabled enrolled in OHP are aware of the ENCC function, and that awareness is also low among providers and others who might contact ENCCs on behalf of enrolled individuals. Figure 3 summarizes these findings by evaluation activities.

OMAP invested substantial resources in the development of the ENCC concept and initial training. However, the state's flexible design for the ENCC role was accompanied by a flexible approach to raising awareness of the role among county agency staff, providers, and elderly and disabled beneficiaries. Rather than aim outreach directly to consumers, State officials conducted training sessions for the local caseworkers, who are the most likely route to ENCC awareness among beneficiaries, including during the plan choice counseling process.

The state also delegated responsibility to disseminate information about ENCC services to the health plans. Plans are required to disseminate ENCC program information to both consumers and providers, although these requirements do not specify the means to conduct outreach. To fulfill this duty, most health plans include information on ENCCs in their beneficiary handbooks, while some sent letters to potential ENCC clients. Some plans discuss the ENCC role in a prominent place in their member handbooks, placing the program title prominently in the table of contents. However, one large plan's member handbook did not list ENCC services in its table of contents, but simply included a brief description of the role in its benefits section. Among all of the handbooks we reviewed none included more than a brief paragraph description of the ENCC role, and only half of these included instructions on how to access ENCC services.

[14] Assessment of the Oregon Health Plan Medicaid Demonstration, Office for Oregon Health Plan Policy and Research, February 1999.

| FIGURE 3: Awareness of ENCC Program Among Beneficiaries and Providers | |
|---|---|
| **Research Activity** | **Findings** |
| **OMAP Mailed Survey of Special Needs Children, 1997** (n=2171 SSI children in managed care) | Less than 10% of parents with special needs children eligible for ENCC services knew of the ENCC function. Only 3% of respondents provided ratings of ENCC, suggesting very little utilization. |
| **OMAP Mailed Survey of Aged and Disabled Adults, 1997-98** (n=2440) | Less than 25% of respondents were aware of ENCC services. |
| **HER/RTI Telephone Survey Of Aged and Disabled Beneficiaries (all ages), 1999** (n= 3309) | Overall, about 25% of respondents indicated "someone at their plan" helped them with social service needs. Rates were higher for respondents age 65+, than for other age groups. |
| **HER/RTI Mailed Survey of Agency Providers** (n=140 agencies) | Less than 30% of respondents were aware of the ENCC program |
| **HER/RTI Focus Groups of Aged and Disabled Beneficiaries, 1998** (n=8 groups, 58 participants) | Many described problems with their health plans, but few respondents were aware of ENCC or had ever contacted ENCCs. |
| **HER Site Visit Interviews (1997-1999)** | Providers were generally unaware of ENCC role and its provisions. ENCCs report few of their referrals or contacts come from physicians or other providers. |

In addition to state and health plan efforts, an ambitious effort to inform beneficiaries of the ENCC role came from the Oregon Advocacy Center, who wrote and disseminated a booklet entitled "To Your Health: Choosing the Health Care that is Right for You." This booklet describes the ENCC role in clear detail, although it provides no telephone numbers. It is unclear how many disabled and elderly beneficiaries received this handbook.

When aged and disabled beneficiaries were first enrolled in managed care, State Mental Health and Developmental Disability Services Division (MHDDSD) staff went to every group home to provide training about managed care and particularly about ENCC services and other consumer protections. However, despite high turnover in group home staff, these trainings have not been repeated. MHDDSD agency case workers could also access ENCCs directly or through SDSD or AAA case workers, yet some disability case workers we interviewed in this system had little experience with ENCCs. Other organizations routinely serve disabled OHP beneficiaries, and those we interviewed had varied levels of awareness and experience with ENCCs. Staff at the Portland Association for Retarded Citizens were familiar with the ENCC role and have frequent contact with ENCCs on behalf of their clients. In contrast, staff we met at another community service agency reported assisting clients with OHP for two years before learning of the ENCC role.

The need to provide ongoing training to these collaborating agencies and providers is great, in part because some beneficiaries' disabilities impede their ability to understand OHP or advocate for themselves. Our beneficiary focus groups included individuals who could not read or understand complicated processes, and others who would not be able to communicate over the phone or use TDD lines due to extensive physical disabilities and communication impairments. It is also easy to underestimate the amount of information that consumers need to absorb to understand the health care system and their coverage. Even well-educated and articulate focus group participants were unaware of ENCC services and some of the other consumer protections under OHP. One participant with a chronic mental illness stated, "I was a corporate attorney, which means I have specialized training in mindless bureaucracy, and I have trouble sorting out this system."

Providers are also potential "users" of ENCC services, who need to be informed of the role. Providers can call on ENCCs to help them work with beneficiaries who do not understand how managed care works, who are having trouble adhering to their treatment plans, or whose needs exceed the mandated benefit. This support appears to be underutilized. ENCCs report that they rarely get calls from providers. Awareness of the ENCC function was low among physicians and agency providers responding to surveys conducted by the State or by HER, or participating in site visit interviews. Low levels of provider awareness is only partly due to a lack of information dissemination. One plan, well aware of this knowledge gap, has tried putting articles about ENCC services in its provider newsletter, but has not seen an increase in ENCC contacts from physicians as a result.

Is it possible that although overall knowledge of ENCC is low, most individuals who need ENCC services are finding them? Not all aged or disabled beneficiaries have problems with their OHP-covered services or need any additional help coordinating their care. We looked at several sources to evaluate this premise and do not believe the evidence supports this conclusion. First, the low levels of awareness overall make it unlikely that all who need ENCC are finding their way to this service. Second, in each of our eight focus groups, participants described problems they had encountered that would have warranted ENCC intervention, yet they were unaware of this resource. For example, a beneficiary confined to a wheelchair due to paraplegia described paying an out of network DME provider for a crucial wheelchair repair. The provider under contract to the plan told him there was a two week wait for repairs and advised him to stay in bed. Had the beneficiary contacted an ENCC, it is likely that the plan would have facilitated timely repair without charge.

We also looked at the relationship between knowledge of ENCC services, health status measures, and access to care in the beneficiary survey conducted by the State. There was no relationship between health status (as measured by general health, mobility impairment, receipt of behavioral health services, number of prescriptions, or having 3 or more physician visits for a chronic health problem) and knowledge of ENCC services. Knowing about ENCC services was associated with knowing about the Ombudsman, and related to satisfaction with access to special equipment, although the

satisfaction rates with access to equipment were still low. Thirty percent of those familiar with ENCC reported it was easy to get special equipment, compared to only 17% of those who were not familiar with ENCC.

## Ongoing Monitoring and Training

The state approach to monitoring has been similar to its program expectations: flexible and collaborative. There are no standard reporting or monitoring requirements, instead the state responds to problems as they arise, often put into motion by the consumer grievance process. Neither does the state collect any encounter data specific to the ENCC program nor are there other consistent quantitative reporting mechanisms. The minimum requirement is that ENCCs must keep charts on each person served. Some plans have ENCC case charts similar to medical records, others record ENCC contacts in a less systematic, narrative fashion. These charts are monitored via record reviews through the Quality Improvement Review process. Since plans vary in their means of keeping charts, it is not possible to compare ENCC data from plan to plan.

As a result of record reviews by OMAP and evaluation findings, OMAP is continuing to adapt their program to assist in serving the target population. In particular they are focusing on Special Needs Children under Title V. Other types of problems identified in the plan review process (for example not attending quarterly ENCC meetings, or inadequate staffing) lead to a corrective plan of action with a definite timeline. This process is followed by monitoring through frequent phone calls, letters and possibly visits.

OMAP invested substantial resources in the development of the ENCC concept and initial training. While continuing to invest in ongoing monitoring and training, OMAP and SDSD staff report the degree of effort to support the evolution of the ENCC role was underestimated and is understaffed. Activities are spread across a number of agencies and functions. These include five full time state Quality Improvement reviewers (whose plan monitoring activities include some review of ENCCs); the Ombudsman staff (4 to 5 FTEs) who work closely with ENCCs on specific case issues; SDSD and AAA staff; and personnel from Mental Health and Development Disabilities Services Division (MHDDSD) and Services to Children and Families (SCF).

OMAP officials feel the current process of ad hoc reviews and survey review is adequate for assessing the program. The state plans to continue to use surveys to monitor awareness of ENCCs. However, we would strongly recommend that a state designing a similar program develop a standard care coordination record at the outset that would support monitoring activities and educate plans to specific types of interventions expected.

The monitoring issue is central to current program debates in Oregon. OMAP officials contend that the state is caught in a dilemma. Advocates, some OMAP staff, and policy makers want accountability. However, this would require developing data

tracking and reporting systems, and then monitoring these systems. Increasing the level of information required would also be burdensome for small plans. Given limited state resources, OMAP faces the challenge of determining whether these resources are better spent on development and monitoring activities or on other activities such as increasing training activities. In addition, it would be challenging to develop indicators by which to evaluate ENCC activities. The State is also reluctant to add any new reporting requirements on top of current HEDIS requirements.

## Current Events and Future Plans

Plan improvements are ongoing and involve a process of assessing consumer issues expressed to the ombudsman's office, input on plan reviews, and issues identified by the Client Advisory Service Unit (CASU). Topics covered in CASU meetings have included how to study program impacts, how to improve training, and increasing plan attendance at ENCC regional meetings. As a result of OMAP's own evaluation findings and information from this HCFA and ASPE funded evaluation, OMAP is particularly concerned about raising awareness of the ENCC program. Oregon officials would also like to extend ENCC services to all OHP beneficiaries enrolled in managed care, but budget cuts would make this difficult. The plans report that many Phase I enrollees (TANF, SOBRA, General Assistance, and expansion population) also benefit from ENCC services, and that it is difficult for ENCC staff to distinguish between enrollees entitled to ENCC services and those who are not covered. Both the State and the plans see this as a testament to the usefulness of the role, and some plans are providing ENCC service to a wider group of enrollees.

# LESSONS LEARNED

Oregon developed and pioneered the ENCC role expressly to assist aged and disabled beneficiaries in managed care. As a pioneer, Oregon had little previous experience to draw on in formulating the ENCC role, and granted the plans broad flexibility to develop and implement the role. With several years' experience, and the opportunity to evaluate various approaches to ENCC implementation, Oregon's experience can provide other states ideas about how to develop similar approaches and possible changes other states might wish to consider. This section summarizes our key findings about implementation of the ENCC role in Oregon and its implications for future policy development.

### Plans developed very different ENCC roles and approaches to providing ENCC services.

The flexibility Oregon afforded the plans is not inherently desirable. Oregon gave the plans considerable discretion in part because no one knew what the ENCC role should look like. The State's openness to variation allowed plans to develop what fit their existing philosophy or worked best for their organizations. Now that there are several years of experience and varied models have been evaluated, states should not hesitate to provide more role definition and articulate their expectations clearly in the contract language. This standardization would provide a more consistent service across the state, provide needed guidance to the plans, and facilitate evaluation of the individual plans.

### The ENCC is only one of several provisions for special populations in Oregon.

Oregon did not implement the ENCC role as a stand-alone feature to assist aged and disabled beneficiaries in managed care. In addition to the ENCC role, Oregon instituted special enrollment procedures, a system of exemptions from managed care, and liberal plan-switching policies for these beneficiaries. ENCCs also work in collaboration with an active Ombudsman program and with the existing local case management system.

### In Oregon, the ENCC role complements and supplements but not intended to replace the local case management system.

Oregon has an extensive county-based case management system responsible for Medicaid eligibility determination and long-term care service authorization (institutional care and home and community-based waiver services are carved out of OHP). Under OHP, the local agency case workers continue to authorize and coordinate these services. They are also responsible for health plan choice counseling, health plan enrollments, and approving health plan exemptions and disenrollments. States that do not have a similar community-based infrastructure

will need to modify the ENCC model to address a wider range of activities than in Oregon

### There are advantages to ENCCs as plan employees.

Oregon designed the ENCC program in the context of an existing case management infrastructure, and did not incorporate long-term care assessment and authorization into Medicaid managed care. While advocates and consumers were initially leery of the ENCC as plan employees (and their satisfaction with current ENCC service varies by plan and by ENCC), most agree that having an in-plan ENCC *can* work and does accomplish things an outside advocate could not. We heard many examples of creative ENCC interventions. As plan representatives, ENCCs have entree to health plan administrators and providers that an outside advocate might not. This advantage is especially helpful to the Ombudsman's office, providing direct access to a health plan representative. Such an in-plan consumer resource may serve other states well in helping Medicaid beneficiaries negotiate the complex provider networks in managed care, as long as specific expectations of the role are clearly articulated in contract language. However, this in-plan care coordination role in Oregon relies on heavily on the presence of the Ombudsman's Office and the community case management system to bring problems to the ENCCs' attention and to advocate on a case by case and systematic basis with the plans. It is not clear that an in-plan ENCC role, without strong external groups working on behalf of the beneficiaries, would be as effective.

### The ENCC role needs more publicity.

Education and outreach efforts need to be widespread and ongoing to educate the public, providers and advocates about the ENCC role. Many beneficiaries rely on agency staff and providers to direct them to appropriate resources like ENCC or to advocate on their behalf. Other beneficiaries have weak ties to the service system and need to receive detailed information directly. Frequent turnover in personnel (such as group home staff) result in a need for ongoing outreach activities. Evaluation findings in Oregon consistently identified low rates of consumer and provider awareness of the ENCC role.

### ENCCs need training and expertise with the populations they serve and knowledge of the community services available.

Some advocates and consumers expressed concern that ENCCs do not share a consistent level of experience or training in coordinating care for the disabled and elderly, and are unaware of the needs of the aged and disabled. Staff functioning as care coordinators for the aged and disabled need to have knowledge of the community service system, clinical issues related to impairment and chronic conditions, the Medicaid benefits, and (for dual eligibles) the Medicare benefits. Some ENCCs also expressed a need for more direction from the State about what types of problems they might be expected to address and examples of appropriate solutions. States, with input from consumers, advocates, providers, and the plans, need to invest in training materials or curricula for ENCCs, as well as requiring plans to staff the role with professional (nurse or social worker) staff.

It is unlikely that member services staff can be consistently and adequately trained to accomplish a significant component of this role. Since there is turnover among plan staff and changes in the community service system, the education and training of ENCCs also needs to be ongoing.

### Contract language regarding ENCC duties must be clear and detailed.

Oregon was not prescriptive because it was pioneering a new role, and state administrators did not have clear expectations for ENCC activities or organization at the plans. As Oregon has gained experience and insight, it faces a lengthy and costly process of revising rules and contracts. Responding to such changes could also be difficult for the plans. Other states should use Oregon's experience to delineate clear expectations that include standardized record keeping and reporting requirements, as well as appropriate ENCC staffing, interventions, and attendance at state training programs.

### Advocates are an important resource in development and implementation

Oregon's collaborative approach to program design included active involvement of the advocacy community. Advocates were able to inform OMAP about important issues in advance, fostering effective program development. Because some disabilities interfere with self-advocacy and use of features like the ENCC, keeping the advocacy community apprized of the resources available and the expectations of the plans is important to increasing beneficiaries' access to covered services.

# REFERENCES


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Mitchell J and P Saucier: *Enrolling Elderly and Disabled Beneficiaries in Medicaid Managed Care: Lessons Learned from the OHP.* Waltham, MA: Health Economics Research, Inc. HCFA Contract No. 500-94-0056, September 1998. [http://aspe.hhs.gov/daltcp/reports/1998/enrlbene.htm]

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# APPENDIX A. CONTINUITY OF CARE REFERRAL

Check all that apply: ☐ PCP Request ☐ Transition Request ☐ ENCC Referral

## Continuity of Care Referral

DRAFT

| | | | | |
|---|---|---|---|---|
| | | Prepaid Health Plan: | | |
| Date | Client's Name (Last, First, MI) | Prime # | SSN | Medicare Parts A ☐ B ☐ |
| DOB | Primary Language | Care Giver/Decision Maker | | Phone |
| Case Worker Name - no load codes | Agency | Phone | Person Completing Referral | Phone |

**Residential Information**

☐ Own Home ☐ Homeless ☐ Group Home ☐ Foster Care
☐ Residential Care ☐ ALF ☐ Nursing Facility

**Primary Care Practitioner Request** (1st & last name) _____

Is client currently a patient of this PCP? _____ Specialist Needs? _____

**Transition Request: Check current supplies, services. List item, vendor & immediate need.**

| | Item | Vendor | Immediate need |
|---|---|---|---|
| ☐ Catheter Supplies | | | |
| ☐ Diabetic Supplies | | | |
| ☐ Incontinency Items | | | |
| ☐ In-Home Care | | | |
| ☐ Ostomy Supplies | | | |
| ☐ Oxygen/Suctioning | | | |
| ☐ Tube Feeding/IV | | | |
| ☐ Ventilator/Trach | | | |
| ☐ Other | | | |
| ☐ Other | | | |

**ENCC Request: check primary area of concern, and provide details in comments section.**

☐ Request for care coordination conference with ENCC
☐ Life-style choice leads to nonparticipation with care, placing client health at risk
☐ Emotional/behavioral mental health condition places health status and/or service access at risk
☐ Language/cultural/sensory issues create a barrier to services or places health status at risk
☐ Medical condition requires intensive monitoring. Please explain below.

**Comments:**

_____
_____
_____
_____

White – Plan/ENCC Yellow – DCO/MHO Pink – Agency File OHP 7207 (11/97)

# DISABILITY SUPPLEMENT TO HCFA EVALUATION OF THE OREGON HEALTH PLAN

## Reports Available

Enrolling Elderly and Disabled Beneficiaries in Medicaid Managed Care: Lessons Learned from the Oregon Health Plan

| | |
|---|---|
| HTML | . |
| PDF | . |

Feasibility of Matching Medicare and Medicaid Data for Dually Eligible Beneficiaries in Oregon

| | |
|---|---|
| Executive Summary | http://aspe.hhs.gov/daltcp/reports/1999/ORfeases.htm |
| HTML | http://aspe.hhs.gov/daltcp/reports/1999/ORfeas.htm |
| PDF | http://aspe.hhs.gov/daltcp/reports/1999/ORfeas.pdf |

The Exceptional Needs Care Coordinator in the Oregon Health Plan

| | |
|---|---|
| Executive Summary | http://aspe.hhs.gov/daltcp/reports/2000/excpneedes.htm |
| HTML | http://aspe.hhs.gov/daltcp/reports/2000/excpneed.htm |
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Office of Disability, Aging and Long-Term Care Policy
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**RETURN TO**:

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[http://aspe.hhs.gov]

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