Designing State-Based Ombuds Programs in MLTSS and the Dual Eligible Demonstrations

A beneficiary perspective from AARP, The Arc, the Center for Medicare Advocacy, Inc., Community Catalyst, the Disability Rights Education and Defense Fund, Families USA, the Medicare Rights Center, the National Committee to Preserve Social Security and Medicare, the National Consumer Voice for Quality Long-Term Care, the National Council on Aging, the National Health Law Program, and the National Senior Citizens Law Center

Managed care is increasingly becoming the vehicle for delivering health and long-term services and supports (LTSS) to seniors and persons with disabilities, including dual eligibles (individuals who qualify for both Medicare and Medicaid). To help this very vulnerable group of consumers navigate the complexities of managed care, beneficiary advocates have consistently urged the inclusion of an independent ombuds[1] as an essential beneficiary protection.

In some states the transition to utilizing managed care to serve this population and provide LTSS is being implemented through a Medicaid waiver. In other states it is being done under the dual eligible financial alignment demonstration. Under either approach, managed care introduces significant and complex changes to the way seniors and persons with disabilities receive care. Including an effective ombuds in Medicaid Managed Long Term Services and Supports (MLTSS) waivers and dual eligible demonstrations will help ensure that these changes improve rather than impede access to care by assisting individual beneficiaries, spotting systemic problems early and giving voice to beneficiary concerns as program modifications are considered.

This paper outlines a beneficiary advocate perspective on the functions an ombuds office in a MLTSS waiver program or a dual eligible demonstration should perform, the elements necessary to make an ombuds work effectively, and options for funding.

The paper also discusses factors to consider when deciding which organization or entity is best suited to perform the ombuds role in any particular state. Finally, the paper highlights a few models for providing effective ombuds services to beneficiaries in managed care.

Why do states need an ombuds program?

Within the next two years, up to two million dual eligibles in as many as 25 states are expected to be enrolled in new demonstration projects that will significantly change the

[1] In this paper we use the term "ombuds," though "ombudsman" is also widely used. We note however that, though these terms are meaningful to advocates and policy makers, neither is very consumer-friendly. States should consider using more accessible terminology when implementing an ombuds program.

way that they receive health and long-term care services. Hundreds of thousands more will be required, via state Medicaid waivers, to enroll in managed care plans to receive most or all of their long-term services and supports (LTSS).

As responsibility for deciding what care will be provided in which setting shifts from state agencies to managed care plans, consumers will need assistance navigating plan procedures and advocates to work on their behalf if errors or mistakes are made. Since managed care plans have limited experience serving this population and, in particular, providing behavioral health and LTSS, there will be systemic challenges to confront and address as new systems mature.

To help meet these challenges, beneficiary advocates have urged the establishment of an independent, conflict-free ombuds for each demonstration. States with established managed care systems have found ombuds programs to be an effective and essential tool in protecting plan enrollees and in helping to better understand and monitor plan performance.[2] An ombuds is even more essential for the plans in waiver and demonstration states that will take on the new responsibility of providing care to extremely vulnerable beneficiaries, many of whom require long-term services and supports.

The term "ombuds" can mean many different things. In this paper, the term refers to an independent, external entity that represents the needs and perspectives of beneficiaries enrolled in demonstrations and MLTSS; a role that is similar to what the American Bar Association refers to as an "advocate ombuds."[3] Housed in an organization outside of the Medicaid agency, the ombuds would provide individuals with free assistance in accessing their care and appropriate services, addressing issues of care quality, and understanding and exercising their rights and responsibilities, and would assist with appeals of adverse decisions made by a plan. Informed by the experience of assisting individuals, the ombuds would identify systemic problems and work with state and plan officials to raise and resolve issues related to state or plan action. The ombuds would collect data about problems and report regularly to state and federal policymakers, creating a valuable complement to oversight and monitoring provided by the authorizing state and federal agencies.

The activities and focus advocates envision for the demonstration and MLTSS ombuds differ from those currently provided by most long-term care ombudsmen, who generally focus their advocacy on care within nursing facilities, assisted living and board and care homes, rather than on ensuring that managed care plans provide access to the wide array of providers and services, especially home and community-based services (HCBS), covered

[2] Existing ombuds programs in Wisconsin and Vermont are among those most directly relevant to the dual eligible demonstrations because they serve similar populations and address MLTSS issues. Contractual and statutory provisions around those two state programs will be noted throughout this paper.

[3] American Bar Association, Standards for the Establishment and Operation of Ombuds Offices (Feb, 2004) at 8, available at www.americanbar.org/content/dam/aba/migrated/child/PublicDocuments/ombudsmen_1.authcheckdam.pdf.

by Medicare and Medicaid. It also is broader in scope compared to Aging and Disability Resource Centers (ADRCs) which offer assistance and navigation but, in most cases, do not include representation in formal appeals, resolution of and tracking of complaints against plans or reporting on problems among their services.

Further, the focus of the ombuds role is different from the current role of most State Health Insurance Programs (SHIPs), which primarily centers on enrollment counseling regarding Medicare, but not Medicaid options, and does not usually include direct representation or reporting on systemic problems. Local legal services programs have experience providing individual representation and recommendations for systems improvements, but many currently lack Medicare expertise.

Distinguishing the role of the demonstration and MLTSS ombuds from existing programs that serve this population is not meant to discourage states and CMS from thinking about how to utilize and expand these organizations when developing an ombuds program. Rather, it is meant to clarify that the ombuds need is not one that is being met by any one organization now. The demonstration and MLTSS ombuds will require a new and separate contract, training, and funding.

What are the core functions for an ombuds?

The three core functions of the ombuds are:

Individual assistance: The primary role of the ombuds should be to give individual members assistance in navigating the complexities of managed care. This role includes assistance in:

- Understanding and exercising rights and responsibilities under the demonstration or waiver and existing civil rights laws, including ensuring physical and programmatic access for beneficiaries with functional impairments and the individual's right to remain in/return to one's community.
- Accessing covered benefits, including troubleshooting for individuals with urgent needs for services.
- Problem-solving for consumers confidentially.
- Resolving billing problems.
- Making enrollment and disenrollment decisions.[4]
- Assisting consumers with appeals at all levels of plan denial, reduction or termination of service decisions.[5]

[4] Pre-enrollment choice counselling is not necessarily part of the ombuds role. These functions could be conducted by the same entity or different entities.

[5] There is evidence that having an ombuds reduces the need for formal appeals. The Wisconsin ombuds reports only 2.6% of its cases were taken to an administrative hearing in its second year and only 1.9% in its third year. Disability Rights Wisconsin, Family Care and IRIS Ombudsman. Program, Year 3 Annual Report, at 1 (Oct. 1, 2011) available at http://dualsdemoadvocacy.org/wp-content/uploads/2012/03/FCIOP-Annual-Report-100111.pdf.

- Raising and resolving quality of care and quality of life issues.
- Ensuring the right to privacy, consumer direction, and consumer driven decision-making.

System monitoring and reporting: The ombuds should provide policymakers and stakeholders an 'on the ground,' beneficiary perspective on how the demonstration or waiver is performing. The program can identify areas where individual problems demonstrate broader issues with system design or implementation. This role includes:

- Tracking of problems reported and assistance provided.
- Rapid identification of urgent systemic problems based on individual requests for assistance.
- Broader identification of system elements in need of reform and unmet consumer care and service needs. Provision of recommendations for improvement.
- Representation of beneficiary perspective and interests in discussion of system modifications.
- Data collection, and analysis.
- Periodic formal reporting to state agencies, state legislatures and the public to inform monitoring and evaluation and systems improvements.[6]
- Providing a public voice for beneficiaries generally.
- In all reporting and tracking functions, protecting confidential consumer information.

Consumer education and empowerment: The ombuds must reach out to, and be a resource for beneficiaries, family caregivers and advocates. It is particularly important that the ombuds establish connections with hard to reach beneficiaries including, but not limited to, those who are limited English proficient, are homeless, are homebound, lack literacy skills, have communication impairments, or are living in institutions.

- Providing outreach to consumers and family caregivers about the availability of ombuds services and education on beneficiary rights in managed care and under Medicare and Medicaid law.[7]
- Building and maintaining relationships with senior, disability, and dual eligible communities and organizations that provide social and other services to dual eligibles and their families.
- Providing information at appropriate literacy levels, in enrollees' languages and in a culturally competent manner.

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[6] Vermont requires both quarterly statistical reporting of cases and quarterly recommendations "for changes to the program or policies and procedures that will benefit consumers." VT Health Care Ombudsman Grant Agreement (hereinafter "VT Contract"). at 4, available at http://dvha.vermont.gov/administration/03410-218-10-final-web.pdf A copy of the most recent annual report of Vermont's health care ombuds is available at www.vtlegalaid.org/assets/Uploads/2012-HCO-Annual-Report-Final.pdf

[7] Exhibit 1 to WI Ombudsman Contract (hereinafter "WI Contract") at 7 and 12, available at www.dhs.wisconsin.gov/LTCare/pdf/ombudsExhibit1.pdf (requiring that ombudsman develop an outreach plan); VT Contract at 6-7.

What qualities are needed in an ombuds office?

- Independence. An ombuds should be located outside the state agency overseeing managed care and not be affiliated with managed care plans.[8] The ombuds should be conflict-free.[9]
- Deep knowledge of Medicare and Medicaid rights, knowledge of the demonstration or waiver structure and requirements, knowledge of appeals systems and rights.
- Legal capability, either through on-staff attorneys or access to attorney resources.[10]
- Systems change focus. Capacity to identify systemic barriers within the health care system and devise solutions to those barriers.
- Trust by the community, extensive ties to consumer and community organizations.
- Aging and disability competences; language and cultural competence.[11]
- Familiarity with disability rights laws and Olmstead community integration and independent living principles.
- Ability to provide telephone, internet and in-person assistance, as appropriate.

What does an ombuds need from the state?

- Funding that permits adequate staffing relative to the population being served. [12] . (See funding discussion below.)
- The freedom to raise individual and systemic issues in any appropriate forum.[13]
- State requirements that both plans and state agencies establish specific pathways for ombuds access and provide timely responses to ombuds complaints and information requests.[14]

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[8] See VT Contract at 5.

[9] Vermont also requires that the ombuds be a non-profit organization. 8 V.S.A. § 4089d.

[10] A requirement that legal services are available to the ombuds office is found in the WI Contract at 11 and the VT Contract at 3.

[11] See WI Contract at 3 and 5 (specific requirements re interpreters, disability competencies and cultural competency training). Hawaii specifically requires that the ombuds phone line greeting offers callers the options of Tagalog, Korean, Ilocano and Mandarin Chinese. Hawaii Ombudsman Services Request for Proposals (May 6, 2010) at 32 (hereinafter Hawaii RFP), available at http://hawaii.gov/spo2/health/rfp103f/attachments/rfp7741273710524.PDF.

[12] Wisconsin uses a ratio of 1 staff member to 2500 enrollees. Wis. Stat. § 46.281(1n)(e); WI Contract at 8-9. The ratios among LTC ombudsmen with oversight over facilities vary greatly, with highly ranked ombudsman programs ranging from 1:1,342 to 1:9,248. See Institute of Medicine, Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act (1995), p. 188, Table 6.1, available at www.nap.edu/openbook.php?record_id=9059.

[13] Wisconsin requires that the ombuds begin with informal advocacy but can go directly to a formal appeal upon the request of the beneficiary. WI Contract at 1. Vermont, by statute provides that "The state ombudsman shall be able to speak on behalf of the interests of health care and health insurance consumers and to carry out all duties prescribed in this subchapter without being subject to any disciplinary or retaliatory action." 8 V.S.A. § 4089f(g)

[14] The Wisconsin Department of Health Services must respond timely to requests by the ombuds program for assistance, consultation or collaboration on individual cases, and must meet regularly with ombuds program staff "to share information about identified or potential patterns of non-compliance issues either with individual MCOs" or with systems. Also, the Department must intervene when an MCO, financial service

- A requirement that state and plan officials participate in regular meetings with ombuds staff.
- Guaranteed access to real time data and records from the state and health plans, including appropriate privacy protections.

Paying for an Ombuds. What are the options?

Potential sources of funding that could be explored include:

- Medicaid. Some states are using Medicaid funding, including federal administrative claiming match, for their long-term care ombuds. This approach would be appropriate for ombuds in states with MLTSS waivers. Medicaid funds part of Vermont's Health Care Ombudsman.
- The Center for Medicare and Medicaid Innovation. CMMI recently announced a funding opportunity for follow-on implementation for the 15 states that received innovation grants and included ombuds programs as one potential element for which CMMI support be sought. Funding for an ombuds should routinely be part of those follow-on grants. More generally, CMMI has a broad mandate and significant resources to fund improvements in care delivery and access and should fund this aspect of the dual eligible demonstrations beyond the 15 states that received design contracts.
- Community Assistance Program (CAP). Although much CAP funding is going to ombuds programs for work on the Medicaid expansion and new Exchanges, CAP funds may be used to provide assistance to individuals on Medicare and Medicaid as well. Several states are using CAP funding to provide support to these populations. Of course, additional CAP funding would need to be provided to ensure that funding is not diluted from current programs, and adequate funding is provided to the programs taking on the additional responsibilities outlined in this document.[15]

Designing an ombuds program: Who is best equipped to perform the core functions?

The decision of what type of organization or organizations would be most appropriate for a demonstration or MLTSS waiver program in a particular state should take into consideration many factors:

- Focus and expertise: The demonstrations and MLTSS waivers are complex involving new rules and procedures as well as continuing rights under two complex programs, Medicare and Medicaid. Issues related to the provision of LTSS, including many specialized disability and behavioral health services, through managed care

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agency, or Aging and Disability Resource Center has refused to timely release information, despite release having been authorized by the enrollee. WI Contract at 15. See also VT Contract at 7 (requiring the state to takes necessary steps "to ensure the cooperation of state agencies" with the ombuds) and 8 V.S.A. § 4089f(d).

[15] See www.healthcare.gov/news/factsheets/2010/10/capgrants-states.html

are likely to be particularly challenging.[16] It is essential that there be a core of dedicated staff immersed in the programs.

- Nature of the demonstration or MLTSS waiver program: The most effective ombuds will have ties and trust in the communities covered by the demonstration or waiver program. Which organization or organizations would be most appropriate could depend on where the program will operate, for example, whether it is concentrated in a few urban counties or is statewide; whom it serves, for example, whether it covers all duals or particular subpopulations and similar factors. An organization serving as ombuds should be a good match with the needs of those being served.
- Size and diversity of the state and the MLTSS waiver or demonstration population: In some states, having a group of organizations working together to provide ombuds functions could be an effective option provided there is close coordination among the cooperating organizations. Although help lines can play a central role in an ombuds program, it is important that there also be some capacity for in-person assistance.
- Leveraging existing resources: Are there already organizations effectively providing navigator and advocacy functions for other programs or populations? How are they organized? Could those resources be leveraged? Could partnerships be formed to perform the functions described above?

There are many examples of programs that provide ombuds or ombuds-like services similar to those discussed in this paper. A few that are illustrative of different types of organizations that have performed similar functions include:

Wisconsin. The protection and advocacy program in Wisconsin, Disability Rights Wisconsin (DRW), operates the ombuds program for individuals under 60 who participate in Wisconsin Family Care and IRIS programs, both of which provide MLTSS. The ombuds operates as a unit in DRW with dedicated staff but can draw on the resources of DRW and the skills of other DRW personnel. DRW receives funding from the state under a contract that is renewed annually. Individuals who are 60 and older are referred to the state's long-term care ombudsman.

Vermont. Vermont Legal Aid has had a renewable grant from the state to act as the Health Care Ombudsman since 1999. After the state established its HCBS waiver program, called Choices for Care, Vermont Legal Aid took on ombuds responsibility for that program as well. Grant funds come from the Department of Financial Regulation, using ACA CAP grant funds and the state's Global Commitment to Health Waiver, which is funded under its Medical Assistance Program Grants. The state recently entered into an additional contract with Vermont Legal Aid to assess operational needs so that the ombuds program can effectively be expanded to address the needs of Exchange consumers.[17]

[16] Wisconsin advocates in the state's ombuds program have reported informally that, although they handle all access to care issues, the vast majority involve LTSS.

[17] See http://dvha.vermont.gov/administration/vt-legal-aid-contract-21803-signed.pdf

Hawaii. The Hawaii Medicaid ombuds is housed in a non-profit, the Hilopa'a Family to Family Health Information Center. Although Hilopa'a was started to serve the needs of families of children with special health care needs, it offers ombuds services to all Medicaid recipients, including enrollees in QUEST Expanded Access, the state's mandatory managed care program for older adults and persons with disabilities. Hilopa'a is one of 51 Family to Family centers nationally that received grant funding from the Health Resources and Services Administration (HRSA).[18] The role of the Hawaii ombuds is more limited than others in that the ombuds may only assist plan members through internal reviews within the plan. The ombuds is specifically prohibited from providing direct assistance with further appeals, although it may refer the member to a legal services provider.[19]

California. California's Health Consumer Alliance (HCA) provides navigation services and advocacy assistance to all Californians, regardless of income or coverage type or lack of coverage. HCA, originally funded with foundation grants, has received funding from the state's Department of Managed Health Care using federal CAP funding. HCA consists of nine consumer centers, each sponsored by a local legal services organization, with leadership by the National Health Law Program (NHeLP) and state support from the Western Center on Law and Poverty. Although HCA is a group of many organizations, it uses a common database to report to the Department of Managed Health Care as well as to identify and address systemic problems.[20]

New York. As in California, New York's CAP grant supports a "hub and spokes" system managed by the Community Service Society and comprised of three specialist agencies and 26 community-based organizations that assist individuals throughout the state to get, keep, and use health insurance.[21] The Medicare Rights Center provides Medicare-specific training and support, and Empire Justice Center and the Legal Aid Society of New York provide additional technical support to all CAP members. Through separate funding from the New York State Office for the Aging, the Medicare Rights Center and six other organizations, including Selfhelp and StateWide Senior Action Council, provide additional support to people with Medicare and others who currently require insurance assistance and will continue to require assistance transitioning from the state's health insurance Exchange to Medicare and Medicaid.

Conclusion

Dual eligible demonstration projects and MLTSS waiver programs are new and complex. Navigating them will be a challenge for beneficiaries. An independent ombuds is an essential consumer protection for seniors, people with disabilities and dual eligibles. Certain common elements are necessary for a successful ombuds, including independence, in-depth program knowledge and strong community links. Other details will vary from state to state. Local stakeholder input and a careful assessment of how to best leverage

[18] See www.hrsa.gov/about/news/2012tables/120523familyvoices.html
[19] Hawaii RFP at 30.
[20] For a description of HCA, go to www.healthexchange.ca.gov/BoardMeetings/Documents/September%2018,%202012/Health%20Consumer%20Alliance%20-%20Comments%20on%20Consumer%20Assistance.pdf
[21] www.communityhealthadvocates.org/about/how-we-can-help.

strengths in the state system will improve program design. In all cases, funding to support adequate staffing and operation is essential.