



American Health Care Association

Issues of Quality in Home- and Community-Based Care

A Continuum of Long-Term Care Options

Persons with chronic conditions or illnesses often have a variety of health, personal care, and social service needs. These needs can be met through a continuum of care options provided at home, in the community, or at an institution. The trend in long-term care is increasingly becoming more consumer-centered, where the focus is more on the needs, circumstances and preferences of the people using care and their families, and to the extent possible, involves them in planning, delivering, and evaluating their long-term care.¹ While consumer-centered care is growing in importance, factors such as access, cost and quality – the three pillars of health policy – continue to influence the availability and choice of care options. Often given less attention among the three pillars, quality is receiving renewed and greater attention.²

Quality of Life or Quality of (Clinical) Care?

But what is quality? In the long-term care sector, the debate over quality chiefly revolves around discussions of the quality of (clinical) care and the quality of life. The most intense debates arise when quality of life issues are at loggerheads with health and safety concerns.

In terms of quality of life and satisfaction with services, care provided in Home- and Community-Based Services (HCBS) settings has been found to be as good or better than care given in institutional settings overall.³ In terms of quality of clinical care, however, the quality of care provided in institutional settings is generally as good as that offered in HCBS settings.⁴ While some studies have shown that HCBS have advantages in terms of increased choice,⁵ behavioral improvement,⁶ improved social interaction,⁷ and enhanced mobility and enhancement in self-care skills,⁸ other studies have shown that HCBS settings have problems related to access,⁹ long waiting lists for care,¹⁰ reduced client functioning and increased dependence on services,¹¹ and possibly greater mortality.¹²

Though the research findings on the comparative quality of care in HCBS and institutional settings is not definitive, what findings thus far do suggest is that one cannot assume that the quality of care in HCBS settings meets the needs of the patient more appropriately than the care provided in institutional settings.

Recognizing that quality of life may be central to a consumer's choice of setting, patient's and their families may be sometimes willing to trade a certain amount of safety and quality in the delivery of clinical care¹³ in order to remain at home in the community and realize a higher quality of life.

Monitoring Quality of Care in HCBS Settings

For any government program providing and paying for HCBS, however, quality of clinical care is as important as quality of life as suggested by a recent report from the U.S. General Accounting Office (GAO).¹⁴ State and federal regulation of institutional settings is well established and, while regulatory requirements contribute to the cost of care in institutional settings, data collected as part of the oversight process provides information to consumers about the level and performance of care available in institutional settings. The GAO report, however, concluded that government oversight of HCBS is inadequate if not, for practical purposes, nonexistent.¹⁵ Part of the reason for the lack of quality monitoring in HCBS settings is due to the difficulty in defining goals and measures and in developing the most appropriate indicators to monitor the quality of care. Monitoring in non-institutional care settings is also difficult due to the dispersed nature of homes and small residential facilities, and the inexperience of state agencies in monitoring non-institutional care.¹⁶ Nevertheless, as HCBS are part of a major program and government is the dominant payer, some aspect of monitoring quality and outcome accountability and money spent needs to be built into the system for the delivery of HCBS.

Quality assessment can be grouped into three aspects: structure, process, and outcome.¹⁷ Structure refers to the underlying capacity to deliver quality care, such as appropriate staffing. Process refers to the appropriateness, intensity, and procedure for the delivery of care. And outcome refers to the extent of the improvement in the patient's condition during and after care. These aspects are important for consumers to evaluate and determine the most appropriate setting for their care needs and for government oversight of the quality of care.

Staffing in HCBS Settings

An important structure-related issue in HCBS settings is related to the delivery of care by paraprofessional staff (i.e. home health aides, homemakers, attendants, personal assistants, etc.). It has been shown that home care workers frequently receive little or no supervision,¹⁸ insufficient training,¹⁹ are often isolated from other agency workers and suffer burnout from job stress.²⁰ As in institutional settings, recruitment and retention of paraprofessional staff is also a problem.²¹ Turnover rates are high.²² Even more so than in institutional settings, workers in HCBS settings receive low wages,²³ few benefits, part-time employment, little recognition, and few opportunities for advancement.²⁴ Further, home care workers often have limited knowledge about the client's condition and care objectives, lack authority to take initiative, and may primarily communicate with case and care managers via the client.²⁵ In addition, because of the fragmented nature of the delivery of HCBS, home care workers occasionally find themselves caught between the directives of the care plan, care and case managers and supervisors, and the wishes of the client or their family.²⁶

The Process of Service Delivery in HCBS Settings and Quality

In an institutional setting, a single provider—the facility—is, at least administratively, responsible for all aspects of a patient's care. By contrast, care in HCBS settings can be more tangled, involving active informal care providers and multiple formal care providers with narrowly-defined care objectives and limited broader control. Consequently, in such a fragmented care delivery system, no single entity often exists to oversee and ensure optimal client care, nor to take responsibility and be accountable for poor client outcomes. Quality of care problems found by the GAO and which appear to be related to the attributes of HCBS include inadequate case management, inadequate assessments or documentation of client needs in the care plan, and failure to provide authorized and necessary services to clients.²⁷ Limited home care worker knowledge about the clients care plan, coupled with infrequent contacts with supervisors and care and case managers may lead to changing patient needs going unrecorded and not communicated.

Although care in institutional settings may also experience similar problems, the structure of HCBS, where services are delivered away from the supervising care and case managers location, may make such problems more acute in HCBS settings. In any case, while HCBS may offer more choice and greater satisfaction, ensuring and monitoring clinical care appears to be more difficult, or at least offers a challenge to the clinician.

The Movement Toward More Consumer-Directed Care

Under the traditional system for the delivery of HCBS services, states contract with home care agencies to provide home care workers, direct services, and monitoring the quality of care delivered to clients. With the rise of the Independent Living Movement in the 1970s, clients began to reject the agency-directed model in favor of a more consumer-directed model where the client could choose the type and relative amount of services to be received. Although consumer-choice of services has implications for the quality of care received by the client,²⁸ research has shown that most consumers prefer to have choice, and are generally more satisfied with services when they have control over the type and provider of services.²⁹ Consumer-directed care is not for everyone, however, particularly clients with cognitive difficulties and some seniors, who may be unaccustomed or uncomfortable hiring, paying, and firing personal assistants.³⁰

¹ Institute of Medicine, 2001. State of Quality of Long-Term Care. In *Improving the Quality of Long-Term Care*. Eds. G. S. Wunderlich and P. O. Kohler. Washington, DC: National Academy Press.

² AAHSA/AHCA/Alliance, 2002. *Quality First: A Covenant for Healthy, Affordable, and Ethical Long Term Care* (<http://www.qualityfirstnursinghomes.com>) Accessed August 19, 2003; CMS (Centers for Medicare and Medicaid Services), 2003. *Nursing Home Compare* (<http://www.medicare.gov/NHCompare/home.asp>) Accessed August 19, 2003; GNS (Gannett News Service), 2003. *Rating America's Nursing Homes* (<http://content.gannettonline.com/gns/nursinghomes/index.html>) Accessed August 19, 2003.

³ Weisert, W. G., C. M. Cready, and J. E. Pawelak, 1988. The Past and Future of Home- and Community-based Long-term Care. *The Millbank Quarterly*, 66 (2), pp 309 – 388; Hollander, M. J., 2001. *Substudy 1: Final Report of the Study on the Comparative Cost Analysis of Home Care and Residential Care Services*. Victoria, BC: National Evaluation of the Cost-Effectiveness of Home Care; Applebaum, R. A., J. B. Christianson, M. Harrigan, and J. Schore, 1988. The Effect of Channeling on Mortality, Functioning, and Well-Being. *Health Services Research*, 23 (1), pp 143 – 159.

⁴ Urciuoli, O., M. Dello Buono, W. Padoani, and D. De Leo, 1998. Assessment of quality of life in the oldest-olds living in nursing homes and at home. *Archives of Gerontology and Geriatrics*, 27 (supplement 6), pp 507 – 514; Hollander, M., N. Chappell, B. Havens, C. McWilliam, and J. A. Miller, 2002. *Substudy 5: Study of the Cost and Outcomes of Home Care and Residential Long Term Care Services*. Victoria, BC: National Evaluation of the Cost-Effectiveness of Home Care; Weissert et al. 1988 (see endnote 3); Hollander 2001 (see endnote 3); Applebaum et al. 1988 (see endnote 3).

⁵ Stancliffe, R. J. and B. H. Abery, 1997. Longitudinal study of deinstitutionalization and the exercise of choice. *Mental Retardation*, 35, pp 159 – 169.

⁶ Kim, S., S. A. Larkin, and K. C. Lakin, 1999. Behavioral outcomes of deinstitutionalization for people with intellectual disabilities: A review of studies conducted between 1980 and 1999. *Policy Research Brief*. Minneapolis, MN: University of Minnesota Institute of Community Integration, 10 (1).

⁷ Anderson, D. J., K. C. Lakin, B. K. Hill, and T. Chen, 1992. Social Integration of Older Persons with Mental Retardation in Residential Facilities. *American Journal on Mental Retardation*, 96, pp 488 – 501; Knobbe, C. A., S. P. Carey, L. Rhodes, and R. H. Horner, 1995. Benefit-Cost Analysis of Community Residential Versus Institutional Services for Adults With Sever Mental Retardation and Challenging Behaviors. *American Journal on Mental Retardation*, 99(5), pp 533-541.

⁸ Braun, K. L. and C. L. Rose, 1987. Geriatric Patient Outcomes and Costs in Three Settings: Nursing Home, Foster Family, and Own Home. *Journal of the American Geriatrics Society*, 35 (5), pp 387 – 397.

⁹ Estes, C. L. and J. H. Swan, 1993. *The Long Term Care Crisis: Elders Trapped in the No-Care Zone*. Newbury Park, CA: Sage Publications.

¹⁰ Institute of Medicine, 2001 (see endnote 1).

¹¹ Weissert et al. 1988 (see endnote 3).

¹² Strauss, D. and T. A. Kastner, 1996. Comparative Mortality of People with Mental Retardation in Institutions and the Community. *American Journal on Mental Retardation*, 101 (1), pp 26 – 40; Strauss, D., T. A. Kastner, and R. Shavelle, 1998. Mortality of Adults With Developmental Disabilities Living in California Institutions and Community Care: 1985 – 1994. *Mental Retardation*, 36 (5), pp 360 – 371; Strauss, D., R. Shavelle, A. Baumeister, and T. W. Anderson, 1998. Mortality in Persons With Developmental Disabilities After Transfer Into Community Care. *American Journal on Mental Retardation*, 102 (6), pp 569 – 581; O'Brien, K. F. and E. S. Zaharia, 1998. Recent Mortality Patterns in California. *Mental Retardation*, 36 (5), pp 372 – 379; Decoufle, P., J. Hollowell, and W. D. Flanders, 1998. Is Community Placement an Independent Risk Factor for Increased Mortality? Comments on Two Recent Reports. *Mental Retardation*, 36 (5), pp 403 – 405.

¹³ Kane, R. A. 2001. Long-Term Care and a Good Quality of Life: Bringing Them Closer Together. *The Gerontologist*, 41 (3), pp 293 – 304; Kane, R. A., R. L. Kane, and R. C. Ladd, 1998. *The Heart of Long-Term Care*, New York: Oxford University; Kane, R. A., R. L. Kane, L. H. Illston, and N. N. Eustis, 1994. Perspectives on Home Care Quality. *Health Care Financing Review*, 16(1), pp 69 – 89.

¹⁴ GAO (United States General Accounting Office), 2003. *Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened*. GAO-03-576. Washington, DC: GAO.

¹⁵ GAO 2003. (see endnote 14).

-
- ¹⁶ Lutzky, S., L. M. B. Alecxih, J. Duffy, and C. Neill, 2000. *Review of the Medicaid 1915(c) Home and Community Based Services Waiver Program Literature and Program Data*. Report Prepared for the Health Care Financing Administration by the Lewin Group. June.
- ¹⁷ Donabedian, A. (1982). The Criteria and Standards of Quality. As cited in Kinney, E. D., J. A. Freedman, and C. A. Loveland Cook. (1994). Quality Improvement in Community-Based, Long-Term Care: Theory and Reality. *American Journal of Law and Medicine*. 22 (1&2). pp. 59 – 77; Jost, T. S. (1989). The Necessary and Proper Role of Regulation to Assure the Quality of Health Care. *Hous. L. Rev.* 25. pp. 525, 533. As cited in Kinney, E. D., J. A. Freedman, and C. A. Loveland Cook. (1994). Quality Improvement in Community-Based, Long-Term Care: Theory and Reality. *American Journal of Law and Medicine*. 22 (1&2). pp. 59 – 77; Kane et al. 1994 (see endnote 13).
- ¹⁸ Cantor, M. and E. Chichin, 1990. *Stress and strain among home care workers of the frail elderly*. New York: Brookdale Research Institute on Aging, Third Age Center, Fordham University. As cited in Eustis, N. N., R. A. Kane, and L. R. Fischer, 1993. Home Care Quality and the Home Care Worker: Beyond Quality Assurance as Usual. *The Gerontologist*, 33 (1) pp 64 – 73; MacAdam, M. and D. Yee, (1990). Providing High-Quality Services to the Frail Elderly: A Study of Homemaker Services in Greater Boston. Waltham, MA: Bigel Institute for Health Policy, Heller School, Brandeis University. As cited in Eustis, N. N., R. A. Kane, and L. R. Fischer, 1993. Home Care Quality and the Home Care Worker: Beyond Quality Assurance as Usual. *The Gerontologist*, 33 (1) pp 64 – 73.
- ¹⁹ Applebaum, R. and P. Phillips, 1990. Assuring the Quality of In-Home Care: The “Other” Challenge for Long-Term Care. *The Gerontologist*, 30 (4), pp 444 – 450.
- ²⁰ MacAdam and Yee 1990 (see endnote 18); Applebaum and Phillip 1990 (see endnote 18); Canalis, O. M., 1987. Homemaker-home health aide attrition: Methods of prevention. *Caring*, 6(4), pp 84-94. As cited in Applebaum and Phillip 1990 (see endnote 19).
- ²¹ Institute of Medicine 2001 (see endnote 1).
- ²² Eustis et al. 1994 (see endnote 17); Knobbe et al. 1995 (see endnote 7); Feldman, P. H., (1988). Beyond Financing: Who will provide long term care. Paper presented at Congressional Briefing Seminar, sponsored by the Gerontological Society of America, Washington, DC. As cited in Applebaum, R. and P. Phillips, (1990). Assuring the Quality of In-Home Care: The “Other” Challenge for Long-Term Care. *The Gerontologist*, 30(4), pp 444-450.
- ²³ Based on data from BLS (Bureau of Labor Statistics, 2001 National Occupational Employment and Wage Estimates), the average wage for a Home Health Aide (\$8.90 per hour) was 6.7 % lower than for a Nursing Aide (\$9.54 per hour) in 2001; See also Crown, W. and M. MacAdam, 1992. *Characteristics and Working Conditions of Aides Employed in Hospitals, Nursing Homes and Home Care*. Paper presented at the 45th Annual Scientific Meeting of the Gerontological Society of America, San Francisco. As cited in Eustis, N. N., L. R. Fischer, and R. A. Kane, 1994. The Homecare Worker: On the Frontline of Quality. *Generations*, Fall, pp 43 – 49.
- ²⁴ Eustis et al. 1993 (see endnote 18); Eustis et al. 1994 (see endnote 17); Applebaum and Phillips 1990 (see endnote 20).
- ²⁵ Eustis et al. 1993 (see endnote 18); Eustis et al. 1994 (see endnote 17); MacAdam and Yee 1990 (see endnote 19).
- ²⁶ Eustis et al. 1993 (see endnote 18); Eustis et al. 1994 (see endnote 17).
- ²⁷ GAO 2003, p. 21 (see endnote 14).
- ²⁸ Tilly, J. and J. M. Wiener, 2001. *Consumer-Directed Home and Community Services: Policy Issues*. Occasional Paper Number 44. Washington, DC: The Urban Institute.
- ²⁹ Doty, P., A. E. Benjamin, R. Matthias, and T. M. Franke, 1998. *In-Home Support Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery*. Washington, DC: U.S. Department of Health and Human Services; Taylor, H., R. Leitman and S. Barnett, 1991. The Importance of Choice in Medicaid Home Programs: Maryland, Michigan, and Texas. As cited in Tilly and Wiener 2001 (see endnote 28).
- ³⁰ Glickman, L. L., K. B. Stocker, and F. G. Caro, 1997. Self-Direction In Home Care for Older People: A Consumer’s Perspective. *Home Health Care Services Quarterly*, 16 (1-2), pp 41 – 54. Tilly and Wiener 2001 (see endnote 28).