

REFERENCES

- Administration on Aging. (2004, June). *The Older Americans Act National Family Caregiver Support Program: Compassion in action*. Washington, DC: U.S. Department of Health and Human Services.
- Arno, P. S. (2002, February). Well-being of caregivers: The economic issues of caregivers. In T. McRae (Chair), *New Caregiver Research*. Symposium conducted at the annual meeting of the American Association of Geriatric Psychiatry, Orlando, FL.
- Baxter, E. C. (2000). Caregiver assessment: Learn about the caregiver, distinct from the person with dementia. *Alzheimer's Care Quarterly*, 1, 62-70.
- Benjamin, A. E. (2001). Consumer-directed services at home: A new model for persons with disabilities. *Health Affairs*, 20, 80-85.
- Blaser, C. J. (1998). The case against paying family caregivers: Ethical and practical issues. *Generations*, 22, 65-69.
- Doty, P. (2004, October). *Consumer-directed home care: Effects on family caregivers*. San Francisco, CA: Family Caregiver Alliance.
- Feinberg, L. F. (2004). Recognizing the work of family and informal caregivers: The case for caregiver assessment. In C. Levine (Ed.), *Family caregivers on the job: Moving beyond ADLs and IADLs* (pp. 67-98). New York: United Hospital Fund.
- Feinberg, L. F., & Newman, S. L. (in press). A study of 10 states since passage of the National Family Caregiver Support Program: Policies, perceptions, and program development. *The Gerontologist*.
- Feinberg, L. F., Newman, S. L., & Van Steenberg, C. (2002). *Family caregiver support: Policies, perceptions and practices in 10 states since passage of the National Family Caregiver Support Program*. San Francisco, CA: Family Caregiver Alliance.
- Feinberg, L. F., & Pilisuk, T. L. (1999, October). *Survey of fifteen states' caregiver support programs*. San Francisco, CA: Family Caregiver Alliance.
- Fox-Grage, W., Folkemer, D., & Lewis, J. (2003). *The states' response to the Olmstead decision: A work in progress*. Washington, DC: National Conference of State Legislatures.
- Gaugler, J. E., Kane, R. A., & Langlois, J. (2000). Assessment of family caregivers of older adults. In R. L. Kane & R. A. Kane (Eds.), *Assessing older persons: Measures, meaning and practical applications* (pp. 320-359). New York: Oxford University Press.
- Glaser, B., & Strauss, A. (1967). *Discovery of Grounded Theory*. Chicago: Aldine.
- Gould, D. A. (2004). Measuring what matters: Levers for change. In C. Levine (Ed.), *Family caregivers on the job: Moving beyond ADLs and IADLs* (pp. 139-149). New York: United Hospital Fund.
- Kasner, E., & Williams, L. (1997). *Taking care of their own: State-funded home and community-based programs for older persons*. Washington, DC: AARP Public Policy Institute.
- Kunkel, R., Applebaum, R. A., & Nelson, I. M. (2004). For love or money: Paying family caregivers. *Generations*, 27, 74-80.
- Levine, C. (2004). Family caregiving: Current challenges for a time-honored practice. *Generations*, 27, 5-8.

- Levine, C., Reinhard, S., Feinberg, L. F., Albert, S., & Hart, A. (2004). Family caregivers on the job: Moving beyond ADLs and IADLs [Appendix]. In C. Levine (Ed.), *Family caregivers on the job: Moving beyond ADLs and IADLs* (pp. 152-165). New York: United Hospital Fund.
- Lewin Group. (March, 2002). *The National Family Caregiver Support Program: Resource guide*. Falls Church, VA: Author.
- Mittleman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *Journal of Gerontology: Psychological Sciences, 59B*, P27-P34.
- Mittleman, S. H., Ferris, S. H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer's disease: A randomized controlled trial. *Journal of the American Medical Association, 276*, 1725-1731.
- Mollica, R. (2003). Coordinating services across the continuum of health, housing, and supportive services. *Journal of Aging and Health, 15*, 165-188.
- Mollica, R., & Gillespie, J. (2003, August). *Single entry point systems: State survey results*. New Brunswick, NJ: National Academy for State Health Policy & Rutgers Center for State Health Policy.
- Montgomery, R. J., & Borgatta, E. (1989). The effects of alternative support strategies on family caregiving. *The Gerontologist, 29*, 457-464.
- National Alliance for Caregiving, & AARP. (2004). *Caregiving in the U.S.* Washington, DC: Author.
- Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *The Gerontologist, 39*, 299-309.
- Petty, D. (1990). Respite care: A flexible response to service fragmentation. In N. Mace (Ed.), *Dementia care: Patient, family, and community* (pp. 243-269). Baltimore, MD: Johns Hopkins University Press.
- Reester, H., Missmar, R., & Tumlinson, A. (2004, April). *Recent growth in Medicaid Home and Community-based Service Waivers*. Washington, DC: The Kaiser Commission on Medicaid and the Uninsured.
- Rosenbaum, S. (2001). *Olmstead v. L.C.: Implications for family caregivers*. San Francisco, CA: Family Caregiver Alliance.
- Smith, G., O'Keeffe, J., Carpenter, L., Doty, P., Kennedy, G., Burwell, B., Mollica, R., & Williams, L. (2000, October). *Understanding Medicaid home and community services: A primer*. Washington, DC: U.S. Department of Health and Human Services.
- Summer, L. (2003, May). *Choices and consequences: The availability of community-based long-term care services to the low-income population*. Washington, DC: Georgetown University, Long-Term Care Financing Project.
- Thompson, L. (2004, March). *Long-term care: Support for family caregivers* (Issue Brief). Washington, DC: Georgetown University, Long-Term Care Financing Project.
- U.S. Department of Health and Human Services. (2002). *Delivering on the promise: Self-evaluation to promote community living for people with disabilities*. Washington, DC: Author.
- U.S. General Accounting Office (2002, September). *Long-term care: Availability of Medicaid home and community services for elderly individuals varies considerably* (GAO Publication No. 02-1121). Washington, DC: Author.

- Vladeck, B. C. (2004). You can't get there from here: Dimensions of caregiving and dementias of policymaking. In C. Levine (Ed.), *Family caregivers on the job: Moving beyond ADLs and IADLs* (pp. 123-137). New York: United Hospital Fund.
- Wagner, D. L. (2001). *Enhancing state initiatives for working caregivers* (Policy Brief No. 5). San Francisco, CA: Family Caregiver Alliance.
- Weiner, J. M., Tilly, J., & Alexih, L. M. B. (2002). Home and community-based services in seven states. *Health Care Financing Review*, 23, 89-114.
- Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology: Social Sciences*, 53B, S267-S277.