POLICY, ADVICE, AND PROGRAMS THAT WORK IN LONG-TERM CARE

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Teaching Dementia Care: Skill and Understanding, by Nancy L. Mace. Johns Hopkins University Press, Baltimore, MD, 2005, 328 pp., $65.00 (cloth), $29.95 (paper).


Books for gerontologists continue to flow from the presses. This review covers a number of long-term care books in relatively distinct domains; policy research and analysis, advice for caregivers, and programs that work.

Policy Research and Analysis

Consumer Voice and Choice in Long-Term Care, according to editors Suzanne R. Kunkel and Valerie Wellin, was inspired by a Robert Wood Johnson Foundation and Scripps Gerontology Center conference on this topic. Some of the papers in this volume were presented at the conference, but others were added to cover subjects stimulated by the conference. The book is divided into three sections: consumer choice, consumer voice; and policy, moral, and legal issues. The first two sections are based on empirical studies of the topics covered, while the final section, as might be expected, draws on literature reviews and legal/moral reasoning.

Carol J. Whitlatch, in her offering “Older Consumers and Decision Making,” examines how caregivers and care receivers compare on their understanding and preferences in care taking circumstances. Her findings are based on a small study of 60 African-American dyads located in Ohio. She concludes that there is no cookie-cutter answer to providing consumer-directed programs because some consumers don’t want a consumer-directed program, and a consumer-directed program may have either positive or negative effects on the caregiver and care receiver in a particular situation. She argues that consumer-directed programs must be evaluated, modified and re-evaluated to insure their efficiency and effectiveness.

Kevin J. Mahoney and Kristin Simone, in part, answer Whitlatch’s call for evaluation in their chapter, “History of and Lessons From the Cash and Counsel-
view of the employed personal assistant. They argue that policy makers and public managers must consider occupational health and safety factors, especially as consumer-directed models of care proliferate. Personal assistance workers have long argued this point, along with the need for good wages and benefits. Public managers operating programs with fixed budgets always face the tradeoff of serving more clients with a poorly-rewarded workforce or serving fewer clients with a higher paid workforce. The only resolution to this conflict is plenty of money.

Kathryn B. McGrew concludes the first section by presenting a model for encouraging persons to engage in long-term care planning before a crisis occurs. She takes us through seven steps to the development of a comprehensive plan. She argues that people must recognize their vulnerability and begin planning before a crisis occurs. That is a laudable objective, but will be difficult to achieve. Pre-planning needs to be supplemented by widely distributing information on long-term care services, so that when the crisis does occur, consumers and families will not have a difficult search process for help.

Section II addresses the questions of whether consumers, be they care receivers or caregivers, are capable of expressing their satisfaction or dissatisfaction and of judging quality. The answer seems to be yes. There are four chapters in this section all based on empirical work ranging from surveys, to face-to-face interviews, to focus groups. Robert A. Applebaum, Gwen C. Uman, and Jane K. Straker draw on data from one national study and one Ohio study of nursing home residents, as well as an Ohio study of home care clients to document that answer. In another chapter, Suzanne R. Kunkel, Kathryn B. McGrew, Robert A. Applebaum, and Shawn L. Davis conducted focus groups with caregivers, care receivers, and support service providers to ascertain the dimensions of quality in home care. They looked at quality of life, quality of services, access, relationships and other items to inform the development of a quality management model for policy makers and managers. They concluded that the perspectives of caregivers, care receivers, and support service providers can be incorporated into such a model and are necessary for its success.

Barbara Bowers, Sarah L. Esmond, Sally Norman, and Elizabeth Holloway report on the Wisconsin Partnership Program, a consumer centered program for frail elders and disabled persons in Wisconsin. They examined the relationship between health care providers and consumers and found that consumers can make critical judgments about the care quality and actually affect the technical provision of care.

Farida K. Ejaz, Dorothy Schur, and Kathleen Fox, in the last chapter in this section, give an account of a study of satisfaction of residents living in independent living facilities located within continuing care retirement communities (CCRCs). This particular subset of CCRCs is rarely studied independently. The study results support the conclusion of the chapters just discussed, that residents are capable of making informed judgments about the quality of their situation. In this instance, the residents identified the importance of resident-staff interaction for a satisfactory quality of life.

It would not be fair to describe the first two parts of this book as cheerleading for consumer-directed care because the articles are fair-minded and based on solid data. It is fair, however, to observe that many critical issues are not discussed. Part III remedies that limitation. Robyn I. Stone, in “Common or Uncommon Agendas: Consumer Direction in the Aging and Disability Movements,” applies her analytic eye to the challenges of consumer direction. After a brief history of the consumer movement, anchoring it in the disability independent living movement of the 1970s, Stone directs the readers’ attention to the issues of cognitive impairment, fraud and abuse, balancing autonomy and safety, quality assurance, worker exploitation and over utilization as concerns needing resolution. These concerns she argues, will ultimately be resolved on political and ideological grounds. Her conclusion is seconded by Chris Wellin, in “Scrutinizing Familial Care in Consumer-Directed Long-Term Care Programs,” where he applies the critical gerontology perspective in his analysis. Using this approach, which demands generational and gender equity considerations, he frames the consumer-directed care question as one of problem definition—who defines what and how. Family care is not necessarily a good thing and, in fact, was something that disabled persons were getting away from when they began the independent living movement. This perspective gets lost if there is too much cheerleading for family care.

Lisa Groger also makes this point in her chapter, “Gifts or Poison? The Cultural Context of Using Public Funds to Pay Family Caregivers,” Groger defines types of cash payments and allowances and examines their generally wide use in six countries: Sweden, Israel, Germany, Great Britain, Canada, and Japan. In contrast to the United States, all of these countries have universal health care, a small to medium private health insurance sector, and a workforce that is heavily unionized. Cash payments to families are embedded in the larger social welfare system of these countries while in the United States, they are exceptional, and are likely to continue to be, given the hostile cultural and political environment to government sponsorship.

Elias Cohen argues that quality is in the eye of the beholder and entertains the reader with changing perspectives on old age as presented in popular music. There are, he says, no magic bullets for producing quality in long-term care, and he inventories some spent bullets that analysts touted not so long ago. Only the hard work of all the usual suspects throwing aside their biases and stretching their minds in concert, will solve our complex problems. We will not be successful, however, if we ignore the legal and ethical realities of consumer direction, warns Marshall B. Kapp in his contribution, “When Consumer Direction Fails: Assigning Legal and Ethical Responsibility in Worst-Case Situations.” Questions of negligence, a duty to limit who can be a consumer, a duty to limit choice, and managing risk are essential concerns in the consumer-directed environment. The parties involved must work
out these problems and a rush to regulatory or legislative solutions could do more harm than good.

This is the go-to book for matters of consumer direction in long-term care. It contains data, answers, and more importantly, questions that need further analyses. The chapters are well-written and interesting with many of them having extensive bibliographies. It belongs on the book shelf of policy analysts, professors, students and managers.

Advice for Caregivers

The four books in this category are aimed at helping caregivers to cope better with the demands of this very emotionally, physically, and economically draining, and usually imposed, vocation. When Your Loved One Has Dementia deserves a truth in advertising award because the authors bill it as “a simple guide for caregivers,” which it is. This 140 page book is an ideal guide to hand caregivers at the time they learn of a loved one’s dementia. It expresses the right tone of sympathy and understanding combined with easy to understand information and useful suggestions. It makes good use of paragraph headings, bullets, check lists, and a few illustrations. The authors are associated with the George C. Glenner Alzheimer’s Family Centers in San Diego, California. They understand their audience and achieve their objective of providing a useful guidebook.

Dementia Caregivers Share Their Stories: A Support Group in a Book, is likewise aimed at caregivers, and adds the actual experiences of caregivers to the simple guide. The book is based on the real life situations of 28 pairs of friends with dementia and their caregivers. The book is organized around the tasks of caregiving including, but not limited to, diagnosis, relationships, handling behavior changes, loss, stress, final transition, and growth through caring. A chapter is devoted to each task and the problems and solutions are presented through the actual experience of friends and their caregiver. New caregivers are likely to find themselves somewhere in these stories, thus allowing them to realize that they are neither unique nor alone—which is the function of a support group. Hopefully, this book would inspire readers to join a real support group. The authors, Lynda A. Markut and Anatole Crane—a clinician and a caregiver—are associated with the Family Alliance, Inc. of Woodstock, Illinois. The book has an index and list of resources.

Barry J. Jacobs, a clinical psychologist, did not realize when he was thirteen that his father’s sudden disability and subsequent death would put him into the state of being a “wounded survivor.” Only while he was in training as a clinical psychologist did he realize the troubling effect of that event on him and his whole family. The experience of this sudden insight set him in training as a clinical psychologist did he realize the state of being a “wounded survivor.” Only while he was

Programs That Work

Do families dump their parents or relatives in nursing homes and then forget them? Does nursing home staff resist involvement of families in patient care? Are there different models of care in nursing homes that really work? These are some of the questions addressed in Promoting Family Involvement in Long-Term Care Settings edited by Joseph E. Gaugler of the school of nursing at the University of Minnesota. This book focuses solely on nursing homes. Neither homecare nor assisted living is mentioned. It offers an analytic framework for examining family involvement programs in nursing homes. There are eleven chapters in the book divided into four sections. These sections are building and refining strategies to involve families, group and family strategies, family-staff partnerships, and the future of family involvement. The book is research oriented with most of the chapters reporting empirical research, and being extensively referenced. Many of the individual chapters have appendices that include instruments, check lists, and scales. The authors of the chapters are based in academic and research settings and represent nursing, social work, sociology, and gerontology. They are each well qualified in the subjects they discuss. Although Gaugler is listed as editor, his role is much more than the gatherer of a set of articles. He has an opening theoretical chapter and a closing one that points to needed program improvements identified by research. Although all of the authors seem to be supporters of family involvement, this does not deter them from critical thinking, and this is no cheerleading effort on behalf of families. This is an important book for anyone conducting research on family involvement in nursing homes.
Unlike Gaugler’s analytic orientation, James Douglas Henry and Linda Gambee Henry give us a descriptive book in *Transformational Eldercare from the Inside Out: Strengths-Based Strategies for Caring*. After an opening section by the editors explaining transformational care, there are 34 individually-authored brief chapters organized under six headings: emerging innovative caring concepts, emerging eldercare communities, higher education and in-house training programs, spirituality and aging, and wide-ranging innovative resources and testimonies. The editors attempt to integrate the chapters with a three-page table in the front of the book, which gives one-sentence descriptions of strategies and page numbers where they can be found. In my opinion the table does not add value. I would classify this book as a set of anecdotal vignettes suitable for persons who like to read such material, but not adding much to the eldercare knowledge base. For gerontology libraries this would be a discretionary purchase.

Nancy L. Mace is coauthor with Peter V. Rabins (2006), of the well known volume *The Thirty-Six-Hour Day: A Family Guide To Caring For Persons With Alzheimer’s Disease, Related Dementing Illnesses, And Memory Loss In Later Life*. In a new book, *Teaching Dementia Care: Skill and Understanding*, she is concerned with training the various professionals who work with families and persons with dementia. She is well qualified to do so, having served as a consultant and board member to the Alzheimer’s Association, and assistant in psychiatry and coordinator of the T. Rowe and Eleanor Price teaching service of the department of psychiatry and behavioral sciences at the John Hopkins University School of Medicine. Now retired, she has authored this teaching resource for trainers of professionals and staff who work with persons having dementia. She rightly states, in my opinion, that this book would serve as a useful text for gerontology students and as a resource for planners and administrators.

The first section of the book prepares trainers to do their own training by reviewing the role of teacher, laying the groundwork for motivation and change, and identifying the special requirements of adult students. This section is geared to motivate the trainer. The second section includes 12 comprehensive lesson plans covering the tasks of dementia care. Her plans parallel the tasks of dealing with caretaking identified by Jacobs, and Markut and Crane in their books discussed above. Each plan has everything the trainer would need to go into the classroom. A typical plan includes objectives, lecture notes, discussion guides, case examples, handouts, and overheads. The book ends with 3 chapters to help trainers become better educators.

An already experienced trainer will benefit from comparing his or her course with Mace’s, and from using insights and media materials. For a novice trainer, there is more than sufficient material in each lesson, thus reducing the need for course development. The novice, however, will have to teach the course three or four times before getting the most out of the lesson material. I have emphasized the comprehensiveness of this book, yet, I am puzzled by the fact that there are no references or suggested literature in the lesson plans. References are relegated to a list of 23, found on one page at the end of the book. This lack, however, does not take away from the value of this book that belongs in every gerontological library and on the shelves of practitioners.

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