

# Consumer Voice and Choice in Long-Term Care

**Suzanne R. Kunkel  
Valerie Wellin**

**Editors**



*This book is inspired by a  
Robert Wood Johnson Foundation-  
and Scripps Gerontology Center-  
supported conference*

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*Edited by*

Suzanne R. Kunkel and Valerie Wellin

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# Contents

Contributors	ix
Acknowledgments	xiii
Introduction	xv

## PART I. Consumer Choice

1. Older Consumers and Decision Making: <i>A Look at Family Caregivers and Care Receivers</i> <i>Carol J. Whitlatch</i>	3
2. Choice and the Institutionalized Elderly <i>Susan C. Reinhard, Sandra Howell White, and Winifred Quinn</i>	21
3. History of and Lessons From the Cash and Counseling Demonstration and Evaluation <i>Kevin J. Mahoney and Kristin Simone</i>	43
4. A Description of Racial/Ethnic Differences Regarding Consumer-Directed Community Long-Term Care <i>Mark Sciegaj</i>	57
5. Case Managers' Perspectives on Consumer Direction <i>Suzanne R. Kunkel and Ian M. Nelson</i>	77

6. **Integrating Occupational Health and Safety Into the United States' Personal Assistance Services Workforce Research Agenda** 89  
*Teresa Scherzer, Susan Chapman, and Robert Newcomer*
7. **Backs to the Future: The Challenge of Individual Long-Term Care Planning** 101  
*Kathryn B. McGrew*

## PART II. Consumer Voice

8. **Capturing the Voices of Consumers in Long-Term Care: If You Ask Them They Will Tell** 127  
*Robert A. Applebaum, Gwen C. Uman, and Jane K. Straker*
9. **Caregivers as Consumers: Perspectives on Quality** 141  
*Suzanne R. Kunkel, Kathryn B. McGrew, Robert A. Applebaum, and Shawn L. Davis*
10. **The Consumer/Provider Relationship as Care Quality Mediator** 153  
*Barbara Bowers, Sarah L. Esmond, Sally Norton, and Elizabeth Holloway*
11. **Resident Satisfaction With Independent Living Facilities in Continuing Care Retirement Communities** 167  
*Farida K. Ejaz, Dorothy Schur, and Kathleen Fox*

## PART III. Policy Issues and Moral and Legal Challenges

12. **Common or Uncommon Agendas: Consumer Direction in the Aging and Disability Movements** 183  
*Robyn I. Stone*
13. **Scrutinizing Familial Care in Consumer-Directed Long-Term Care Programs: Implications for Theory and Research** 195  
*Chris Wellin*

14. <b>Gifts or Poison? The Cultural Context of Using Public Funds to Pay Family Caregivers</b> <i>Lisa Groger</i>	221
15. <b>Response to Quality: Differing Definitions</b> <i>Elias S. Cohen</i>	233
16. <b>When Consumer Direction Fails: Assigning Legal and Ethical Responsibility in Worst-Case Situations</b> <i>Marshall B. Kapp</i>	251
<b>Index</b>	261

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# Introduction

Consumer voice and choice have emerged as important and timely factors in (and arguably a wholly different approach to) the design and delivery of long-term care services to elderly and disabled populations. Opportunity for consumers to provide input about their services within the traditional system is a defining element of consumer voice. Hearing from consumers about the quality of, and their satisfaction with, their services has become an essential component of quality management in many sectors of long-term care. Providing service delivery options so that long-term care consumers can truly have choice has required more fundamental changes to the long-term care system. Consumer direction is an innovative service model which emphasizes that autonomy, choice, and less restricted access to services and support are rights of long-term care recipients rather than simply value-added benefits.

Greater involvement and control by consumers in directing and assessing their own care is timely, as this approach, which began with a younger disabled population, has now taken root in the older cohorts including our current seniors and the aging baby-boom generation. Publicly funded consumer-directed programs continue to proliferate. Based on a recent survey of 40 states, three-fourths of those states now offer consumer-directed home- and community-based services for older people; 20 states offer two or more consumer-directed options within their home-care system for older adults (Infeld, 2004). Cash and Counseling, the most fully developed and fully articulated model of consumer direction, is currently being implemented in 15 states. In Cash and Counseling programs, consumers hire and supervise their own workers, direct their own services, and manage their own purchasing plans. Participants receive assistance with these tasks from fiscal intermediary agencies, support brokers/counselors, and, if appropriate, authorized representatives.

What will this emergent approach to long-term care require of its many and varied stakeholders? In short, a great deal. To insure the active role of consumers in the assessing of services and programs, academic and agency-based researchers will need a variety of new and retooled instruments and strategies. Consumer-centered valid and reliable instruments, and effective data collection approaches, are crucial if consumer voice is to be heard in the design and evaluation of quality of care delivered to a vulnerable or at-risk population. Commitment to a new model of service delivery—with all that implies, and by all those involved in the design and implementation of long-term services—is essential. Program administrators, clinical and social service personnel, and other direct-care workers all play crucial roles in making consumer voice and choice a reality. Ensuring their awareness of, commitment to, and role in this innovative approach will be crucial to its success. Policy makers and agency leaders are facing ideological, political, and pragmatic challenges in supporting the shift to consumer-centered service delivery.

This book is intended to serve as a resource as the field of long-term services for older adults increases its commitment to consumer empowerment. This volume describes current research, practice, and critical thought related to consumer voice and choice in long-term care. We envision a broad target audience for this publication, including gerontology, health care and social science students, practitioners/professionals who work in the long-term care industry, policymakers, researchers, and a growing number of people seeking to take an active (even proactive) role in their own care or in the care of others who are close to them.

This book was inspired and informed by a conference—“The Consumer Voice and Choice Conference,” which was organized by the Scripps Gerontology Center, and sponsored in part by the Robert Wood Johnson Foundation. In recognizing the evolving and expanding role of consumers in long-term care, the editors of this book have used the conference as a springboard to further explore consumer direction in long-term care. Topics include approaches to capturing and measuring consumer satisfaction and quality, case management, quality improvement, and decision making and planning. Some of the chapters in this book are based on presentations that took place at this conference; other chapters have been added to give a more comprehensive view of the topic.

The book is organized in three parts. Part I, “Consumer Choice,” includes factors that may influence an individual’s role in planning for their own long-term care needs, the extent to which an older person wishes to be involved in their long-term care, their preferences for service models and for control over specific types of services. This section also describes consumer direction as a model of long-term care service delivery. One chapter describes the Cash and Counseling initiative; another discusses

the challenges facing case managers as they shift their role to supporting self-directed consumers. This section also offers a chapter that focuses on the well-being of workers in consumer-driven home care, and assesses a state initiative that helps nursing home residents return to the community by giving consumers and their families information about their long-term care options.

Part II, “Consumer Voice,” explores the value of, and approaches to, ascertaining the needs, preferences, and perspectives of long-term care consumers in both institutional and community settings. This section includes research in the development of instruments for measuring satisfaction among consumers (including consumers with dementia), family members, and caregivers. Another subject related to the understanding of satisfaction measures and included in this publication is an exploration of the consumer/provider relationship and its relation to the consumers’ perception of care quality.

Part III offers broad, critical, and thoughtful works on the significant changes that consumer voice and choice bring to long-term care. These authors discuss the possibility for a common consumer-centered agenda across all age groups and populations receiving long-term services, the cultural and ideological factors at play in the debate about paying family caregivers, and the challenges of defining quality from the perspectives of multiple stakeholders. This section also includes a chapter that challenges us to consider situations in which consumer self-direction is not successful. One of the authors in Part III draws on personal experience and theoretical perspectives to analyze the ways in which we structure, define, stratify, and commodify work in long-term care.

Any change in social policy—particularly change that is responsive to issues of autonomy and choice in publicly funded programs such as in consumer direction, and which addresses the needs of those with serious, chronic disabilities—can be expected to evoke strong and varied reactions. More, the reactions will reflect the interests and perspectives of various stakeholders who are involved in the change. To weigh and reconcile various aspects of this policy, we need multiple angles of vision on consumer direction. Researchers need guidance on how to study and evaluate such programs; practitioners need information on how they can best fulfill their professional roles in a changing long-term care system; policy advocates and the general public need to consider the practical and also ethical issues they must face in protecting vulnerable people. In this volume, we hope to have made steps toward addressing and clarifying both the broad range of questions and the varying and sometimes opposing perspectives of stakeholders regarding consumer direction in long-term care.

**REFERENCE**

Infeld, D. L. (2004). *States' experiences implementing consumer-directed home and community services: Results of the 2004 Survey of State Administrators, Opinion Survey and Telephone Interviews*. Washington, DC: National Association of State Units on Aging and The National Council on the Aging.

P A R T I

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**Consumer Choice**

# Older Consumers and Decision Making:

## *A Look at Family Caregivers and Care Receivers*

Carol J. Whitlatch

*“We have a family discussion before we make any major decision about my care. I get good care from my family.”*

—78-year-old woman with dementia, cared for by her  
56-year-old daughter

### BACKGROUND

Families play a central role in both the decision making and delivery of long-term care to the estimated 13 to 15 million Americans with adult-onset cognitive impairment (e.g., Alzheimer’s disease, stroke, Parkinson’s disease, traumatic brain injury; Family Caregiver Alliance, 1999). Despite the magnitude of the number of persons living with cognitive and physical impairments, we know very little about how families make decisions about everyday care. According to Kane (1995, p. 89), “In long-term care, both the older person who perceives a need for help and family members who may decide to provide care have decisions to make. One decides whether to accept care; the other, whether to give it. Each is influenced

by the other, sometimes by explicit advice and sometimes by influences about what is important to the other.” Few studies exist that examine the types of daily care decisions that family caregivers and care receivers make, especially when cognitive impairment is involved (Young, 1994).

Loss of cognitive and functional abilities affects the individual and his or her family in profound ways. For example, balancing the needs and preferences of the impaired person with the needs and preferences of the family caregiver can be exceedingly complex. Often at great personal sacrifice, families strive to keep a loved one at home, sometimes to avoid more costly institutional care. One of the most difficult problems a family caregiver faces is making decisions for a loved one whose capacity for planning and judgment may be impaired. Often, conflicting factors must be weighed. The following questions illustrate the nature of the conflicting need between caregivers and care receivers. *Is there a potential for risk or harm to my wife or others? How do I reconcile her wish not to let anyone in the house, with my need for help with her care?* There are no simple answers to these questions. In practice, it is oftentimes difficult to separate the needs, preferences, and best interests of the person with dementia from the needs, preferences, and best interests of the family.

Family caregivers often have a limited understanding of the needs and preferences of the relatives for whom they provide care. Caregivers may have a general understanding of what is important but do not necessarily know how important certain care values and preferences are to their relatives (Feinberg & Whitlatch, 2001; Whitlatch, Feinberg, & Tucke, in press). Adding to this already stressful situation is the reality that families have very few service options that take into account, let alone enhance, the autonomy of both caregiver and care receiver. More typically, but not always, services provide some level of choice to either the caregiver OR the care receiver. The number of services that are considered *consumer directed* is slowly increasing as both consumers and providers begin to appreciate the value of consumer direction in both community-based and residential long-term care environments.

This chapter introduces the concept of consumer direction (CD) as it applies to community-based family caregivers and the persons for whom they provide care. First, the chapter provides a brief overview of the stresses associated with family caregiving and then moves to a description of the concept of CD and the issues surrounding its development and utility within community-based programs for caregivers and care receivers. Next, the issues surrounding the implementation of consumer-directed care are discussed including family decision making when cognitive impairment is involved, the emergence of *person-centered care*, and the challenges of implementing consumer-directed programs that simultaneously serve both the caregiver and the care receiver. Third, the question is posed

and discussed: *do all caregivers and care receivers want consumer-directed options?* Fourth, a brief description is given of a study that examines the care values and preferences of care receivers and whether their caregivers understand these values and preferences. The chapter ends with a discussion of the key issues to consider when designing and implementing consumer-directed programs for caregivers and care receivers.

## RESEARCH ON CONSUMER DIRECTION FOR BOTH THE CAREGIVER AND CARE RECEIVER

*“The hardest thing is the dependence of my parents on me. Their expectations are way too high, too much for one person. I have no time for my own life.”*  
—54-year-old daughter caring for her 83-year-old mother  
with memory problems

More and more families are facing the economic and emotional costs of providing long-term care. At the same time people with cognitive and physical disabilities are making strides toward greater autonomy through consumer-directed care. The concept of CD in home and community care is based on the key elements of choice, control, autonomy, and the philosophy that informed consumers make choices about the services they receive (National Council on the Aging, 1996). Consumer direction implies that consumers prefer to make decisions about their service needs and are able to take a more active role in managing their own services. This trend in CD is an outgrowth of the Independent Living Movement, which began in the 1970s primarily with younger adults with physical disabilities (DeJong, Batavia, & McKnew, 1992; Simon-Rusinowitz & Hofland, 1993). More recent initiatives have been successful in bridging the aging and disability communities (National Council on the Aging).

Consumer direction implies that the consumer should be presumed competent to make choices. Yet, “the presumption of competence also means that a consumer’s decision to delegate responsibility for directing certain aspects of service provision to other persons can be a consumer-directed choice, in the right circumstances: for example, where a person with cognitive impairment has a family member acting as a consumer on his or her behalf” (National Council on the Aging, 1996, p. 7). Thus the notion of who is the *consumer* in long-term care is an important policy and practice issue for those designing and testing long-term care service delivery systems and interventions for persons with cognitive impairment and their informal caregivers.

In recent years, research on health care preferences, decision making, and CD has expanded in a variety of directions. Past research on CD has

focused largely on end-of-life medical care in acute settings. Preferences for and decisions about do not resuscitate orders or naming a health care proxy make up the majority of this research. In contrast, few studies have examined day-to-day care preferences and decision making. Yet, some of the most difficult decisions and conflicts for persons with cognitive and/or physical impairment and their families arise in everyday long-term care at home and in community-based settings. Deciding when to bathe, what to wear, whether to purchase and use support services (e.g., in-home care or adult day services), or when to accept care from family members are examples of difficult everyday care decisions that families must make. Tremendous family conflict can occur as the care receiver progressively declines in his or her ability to carry out such daily activities as managing money, driving, or cooking. For persons with cognitive impairment, decisions and preferences about everyday care become increasingly difficult to communicate as their disease progresses and their cognitive and functional abilities deteriorate.

Questions about the family's role in home- and community-based care are complex when the person being cared for has cognitive impairment because, frequently, the family becomes both the *decision maker* and the *service provider*. According to Kapp (1996), empowering the person with cognitive impairment often means empowering his or her family support system. Past research suggests that most—but not all—adults want a family member to make health care decisions for them if they are not able to make decisions themselves (High, 1988; Louis Harris and Associates, 1982). Some care receivers, however, have no family, whereas others have families who are unable or unwilling to assume the decision-making role (Feinberg & Whitlatch, 1998). Nevertheless, few care receivers make decisions entirely without the assistance of others. It is important to understand the various roles of family members and other informal caregivers in the decision-making process when a relative has physical and/or cognitive impairments (Feasley, 1996). Thus, if consumer-directed services are to be successful, it is necessary that the providers of the services recognize the interdependence of the caregiver and care receiver.

Although very few research studies have examined the views and care preferences of persons with dementia, there are a growing number of studies that emphasize the importance of control, autonomy, self-care, and consumer-directed services (Eustis, 2000). The absence of the care receiver's perspective has led to a lack of representation of their needs in the selection of care strategies (Cohen, 1991). One reason for this oversight is that researchers have only recently begun to recognize and include persons with cognitive impairment as *legitimate contributors* in the research process (Cotrell & Schulz, 1993). As Woods (1999, p. 36) has noted, "there has been the assumption that people with dementia are unable to

communicate in a meaningful way, invalidating their participation in decision making about their own situation as well as rendering their lived experience and their perspective as being impossible to research.” According to Stewart, Sherbourne, and Brod (1996), subjective assessment in cognitively impaired populations has been ignored because of the presumed logistical and methodological issues, specifically regarding comprehension and reliability. Sadly, researchers and practitioners often wrongly assume that persons with cognitive impairment are unable to make care decisions for themselves. As a result, there are very few model consumer-directed programs that recognize the impaired adult’s voice in decision making.

Recently, however, in both research and practice, there has been a move to understand the preferences and experiences of persons with dementia (Downs, 1997; Kitwood & Benson, 1995; Woods, 1999). The majority of the literature on the emergence of the person in dementia research is qualitative in design. Downs (1997) outlines three areas that have been studied: (1) the individual’s sense of self, (2) perspectives of persons with dementia, and (3) a person’s rights. In terms of sense of self, a growing body of research suggests that people with dementia retain a sense of self, despite cognitive impairment, into the late stages of the illness (Downs; Kitwood, 1997; Woods, 1999). Further evidence that persons with dementia are able to report on their situation comes from the growing number of support groups and other services developed specifically for persons with early-stage dementia (Brod, Stewart, Sands, & Walton, 1999; Yale, 1999). Downs (p. 605) notes that although more attention has recently been paid to the perspectives of persons with dementia, there is a “clear bias towards eliciting views from people in the early stages.” Last, there is a growing trend acknowledging the rights of people with dementia (Downs). A gap still exists, however, in exploring the person’s values, preferences, and decision making for daily care situations.

To date, no valid, standardized method exists to determine decisional capacity (Gerety, Chiodo, Kantan, Tuley, & Cornell, 1993; Kapp & Mossman, 1996). In home- and community-based care, capacity is oftentimes best assessed on a decision-specific basis, where some persons with cognitive impairment may have decisional capacity in some respects but lack capacity in others. For example, Mrs. M. may be able to decide who should make health care decisions for her if she is no longer able, but not competent enough to shop for groceries. Because of the intellectual impairment that characterizes most dementing illnesses, the capacity to make decisions about daily activities is often compromised (Zarit & Goodman, 1990). When cognitive impairment is mild, questions may arise about the care receiver’s ability to perform certain activities (e.g., to continue working or handle financial affairs). If cognitive functioning further deteriorates, care receivers are faced with decisions about daily life activities

that may jeopardize the safety of both the person with cognitive impairment and others (e.g., driving and cooking; Zarit & Goodman). In the advanced stage of dementia, for example, language deficits limit the individual's ability to communicate. Unless the care receiver had previously expressed preferences for everyday care, it is nearly impossible to know what the individual wants and needs (Cotrell & Schulz, 1993).

Although it appears that care receivers with mild to moderate cognitive impairments are able to voice their preferences and make informed decisions about a variety of care-related issues (Brod et al., 1999; Cohen & Eisdorfer, 1986; Gerety et al., 1993; Logsdon & Teri, 1996; McHorney, 1996; Parmlee, Lawton, & Katz, 1989; Sansone, Schmitt, & Nichols, 1996), the impact of this consumer-driven movement on family caregivers is unknown. Does empowering the care receiver lead to a disempowered caregiver? Is care receiver and caregiver empowerment mutually exclusive? Preliminary evidence suggests that increased involvement in decision making by care receivers is associated with higher levels of caregiver depression (Whitlatch, 1999). To illustrate, a daughter caring for her mildly demented father may find that his involvement in decision making is counter to her own best interests. She may wish to make all decisions herself, for example, preferring for her father to remain safe at home with paid assistance. The father might prefer to be alone during the day and check in with his daughter hourly by telephone. When do his rights to consumer-directed care supercede her rights and vice versa? Does his previously voiced preference to remain at home rather than be placed in a facility override her preference if his home care becomes too much for her? Often, one's assessment of need changes according to circumstances making it particularly difficult both to project future change in circumstance and to anticipate evolving preferences and options to those changes (Hibbard, Slovic, & Jewett, 1997). Again, there are no easy answers to these very real questions and dilemmas.

### **DO CAREGIVERS AND CARE RECEIVERS WANT CONSUMER-DIRECTED OPTIONS?**

*"I have no personal or down time. It is affecting my health. If I had some more personal time, I could do a better job of caregiving."*

—66-year-old wife caring for her 65-year-old husband  
with memory problems

It is widely assumed that family caregivers and care receivers prefer service delivery options that include consumer-directed models. This assumption is a product of the trend toward increased self-determination and consumer direction. However, there are a number of factors that may be

linked to a person's interest in receiving consumer-directed services. Research suggests that cost plays a central role in determining access to and interest in receiving care, and in the type and duration of care received (Advisory Panel on Alzheimer's Disease, 1992; Wilson, 1995). But how do costs influence family caregiver and care receiver preferences for and decisions about the use of consumer-directed home and community-based care? Results of recent research on consumer choice for family caregivers indicate that the direct pay (i.e., consumer-directed) model of in-home respite is the preferred mode of service delivery (Feinberg & Whitlatch, 1998). Caregivers who preferred the consumer-directed option were more likely to be employed outside the home and more likely to be of an ethnic minority group. Moreover, the consumer-directed model was more cost effective than the agency-based respite care model (Feinberg & Whitlatch). Specifically, caregivers who used the consumer-directed option received more hours of respite care than caregivers who used agency-based respite. In addition, compared to agency-based respite, the direct-pay option was shown to be significantly less costly per hour of service. On the other hand, results also suggested that caregivers in both groups (i.e., direct-pay and agency-based users) valued safety concerns and good, reliable, and trustworthy help over cost issues and amount of care. Thus, cost of care is just one of many critical factors that families consider when they are choosing the care options that best fit their needs.

Autonomy, choice, and consumer-directed options are important to community dwelling consumers as well as to those living in residential settings. Findings from a study of nearly 300 long-term care receivers suggest that consumers had clear preferences for both initial and continued control over personal decision making (Salmon & Polivka, 2000). When given three options for how care should be provided, one-third (34%) of home care consumers preferred consumer-directed options, 13% preferred a traditional agency model, and the remaining showed no preference or did not like any of the three models (Salmon & Polivka). Similarly, Simon-Rusinowitz and colleagues (1997; Simon-Rusinowitz, Bochniak, Mahoney, Marks, & Hecht, 2000) suggest that a sizable number of the older consumers they interviewed were interested in consumer-directed options.

Yet, not all older adults prefer consumer-directed program options. This is true for persons regardless of ethnicity, age, and cognitive ability. Research that examined elder judgments to questions regarding community long-term care showed significant racial and ethnic group differences regarding desire for and satisfaction with control over the amount, type, and manner of care (Sciegaj, 2001). African American, Latino, and White elders who were receiving community-based case management services reported a preference for traditional models of care rather than more consumer-directed models (e.g., cash and counseling). Chinese elders

were equally likely to prefer a Social Health Maintenance Organization (SHMO) model (47%) or a traditional model (50%) to a more consumer-directed model of community care (Sciegaj). In this case, the elders' preference for the SHMO and traditional models may be accounted for by their having received care from culturally appropriate care agencies (Sciegaj). More recently, Sciegaj, Capitman, and Kyriacou (2004) report that elders, regardless of racial and ethnic background, who desire control over in-home care workers are less likely to select a traditional case management service option. The findings of these studies suggest that community long-term care judgments are the result of a complex configuration of racial, ethnic, and gender differences in social experiences that have not been captured in previous studies.

In general, few studies examine how families make decisions about everyday and long-term care. Central to this issue is the question of whether caregivers understand their relatives' care values and preferences. We next move to a discussion of preliminary findings from one of the first studies to examine care receiver's values and preferences for care from the perspective of both caregivers and care receivers.

### **CAREGIVER AND CARE RECEIVER VALUES AND PREFERENCES FOR CARE**

*"I need a break, some time to get away with assurance that mother is in safe hands."*

—50-year-old daughter caring for her 71-year-old mother

Following the work of Ogletree (1995), Degenholtz, Kane, and Kivnick (1997, p. 768) define "*values* as broad beliefs about features in the everyday world to which people attach importance, and *preferences* as more specific choices that flow from values." Drawing on this definition, we developed the *Values and Preferences Scale* from previous work with cognitively intact samples (Degenholtz et al.; Kane & Degenholtz, 1997; McCullough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993). Exploratory factor analyses of the caregivers' responses indicated that the 37 items of values and preferences in everyday care that the care receiver felt were "very important," "somewhat important," or "not at all important" could be collapsed into four conceptual domains:

1. Self identity/Environment (10 items, alpha = .71)
2. Autonomy (9 items, alpha = .80)
3. Burden (4 items, alpha = .70)
4. Family and social network (14 items, alpha = .79).

**Table 1.1** Top Seven Values and Preferences Scale Items for Care Receivers (CRs) and Caregivers (CGs)

	CR	Mean	CG	Mean
Be safe from crime	1	2.91	4	2.87
Have a comfortable place to live	2	2.90	3	2.90
Feel safe in home, even if it restricts activities	3	2.89	2	2.91
Maintain dignity	4	2.81	1	2.92
Be in touch with others in case of emergency	5	2.78	8	2.66
Have reliable help	6	2.75	5	2.75
Have caregiver be the one to help out	7	2.74	6	2.73
Not live in a nursing home	13	2.53	7	2.69

The sample for which the following results are drawn consisted of 60 African American family caregiver–care receiver dyads from northeast Ohio. To be eligible for the study, African American older adults had to (1) have one or more chronic health conditions (e.g., diabetes and high blood pressure), (2) have symptoms of memory problems or an adult-onset brain disease or disorder (e.g., Alzheimer’s disease, stroke, and Parkinson’s disease), (3) be living at home rather than an institutional setting, and (4) be mildly to moderately cognitively impaired (scores between 13 and 26, on the Folstein Mini-Mental State Exam). Caregivers had to be the primary nonpaid caregiver for the cognitively impaired adult.

Table 1.1 lists the seven most important Values and Preferences items for care receivers and caregivers. For care receivers, the top seven items were “Be safe from crime” (2.91), “Have a comfortable place to live” (2.90), “Feel safe in home, even if it restricts activities” (2.89), “Maintain dignity” (2.81), “Be in touch with others in case of emergency” (2.78), “Have reliable help” (2.75), and “Have caregiver be the one to help out” (2.74). For caregivers, the top seven items were, “Maintain dignity” (2.92), “Feel safe in home, even if it restricts activities” (2.91), “Have a comfortable place to live” (2.90), “Be safe from crime” (2.87), “Have reliable help” (2.75), “Have caregiver be the one to help out” (2.73), and “Not live in a nursing home” (2.69). At the group level, item means for the care receivers and caregivers were often slightly different. Yet, none of the item means for the seven highest ranked items were significantly different (see Table 1.1).

Next, responses of care receivers were compared to the responses of caregivers on each of the 37 items in the Values and Preferences scale. T-tests determined whether there was congruence or agreement between care receivers and caregivers. In other words, if there were significant

**Table 1.2** Care Receiver and Caregiver Values and Preferences Item Means and Significant t-values

	Care Receiver	Caregiver Mean	t-value
<b>Autonomy</b>			
Use services only covered by insurance	2.18	1.71	-3.531**
Have say in excluding family or friends from helping	2.05	2.39	3.705**
<b>Burden</b>			
Have money to leave to family	2.00	1.64	-2.685*
Caregiver not put life on hold	2.65	2.40	-2.037*
<b>Self-identity/environment</b>			
Do things for self	2.68	2.38	-2.562*
Have something to do	2.50	2.10	-3.584**
Use services can pay for by self	2.25	1.75	-3.521**
<b>Family/social network</b>			
Do things with other people	2.39	2.12	-2.376*
Maintain continuity with the past	2.17	2.44	2.167*

\* $p < .05$ .\*\* $p < .01$ .

differences in how important the caregivers thought the item was to the care receiver and how important the item actually was to the care receiver, the item was considered incongruent. Significant differences were found for 9 of the 37 items (see Table 1.2). Typically when there were significant differences, the care receiver placed greater importance on the item than the caregiver thought they did. For example, care receivers felt the item "Caregiver not put life on hold" from the Burden subscale was significantly more important than caregivers felt it was to care receivers (2.65 vs. 2.40,  $p < .05$ ). One exception to this trend is that caregivers placed greater importance on their relative's "Maintaining continuity with the past" (2.17 vs. 2.40,  $p < .05$ ). No items from the Environment domain were found to be significantly different.

The sample was next divided by kin group (dyads with spouse caregivers,  $N = 35$  and dyads with adult child caregivers,  $N = 16$ ) and  $t$ -tests were again performed between caregiver and care receiver responses for each group. Dyads with spouse caregivers yielded significantly different care receiver and caregiver answers on 10 of the 37 items. The dyads with adult children caregivers had significantly different answers on 12 of the 37 items. As with the sample as a whole, when there were significant differences, the care receivers typically placed greater importance on the item than the caregivers thought they did. One exception to this trend appeared on one item in the dyads with spouse caregivers. Here,

the spouse caregivers believed the care receivers placed more importance on “Maintain dignity” than care receivers actually did.

Finally, adult child caregivers’ responses were compared to spouse caregivers’ responses for each item in the *Values and Preferences Scale*. Significant differences between adult child caregivers and spouse caregivers were found for only four items, “Live in own home” (adult child mean = 2.50, spouse mean = 2.91,  $t = -2.69$ ,  $p = .010$ ), “Be in touch with others in case of emergency” (adult child mean = 1.81, spouse mean = 2.29,  $t = -2.17$ ,  $p = .035$ ), and “Have time to self” (adult child mean = 2.44, spouse mean = 1.97,  $t = 2.49$ ,  $p = .016$ ), and “Have caregiver be the one to help out” (adult child mean = 2.63, spouse mean = 2.94,  $t = -2.67$ ,  $p = .010$ ). There were no significant differences between the responses of care receivers with adult child caregivers and care receivers with spouse caregivers.

The findings from this study indicate that family caregivers have a fairly accurate view of the care values and preferences that are important to their relatives. However, caregivers are less accurate in their perceptions of *how* important certain values are to their relatives. Typically, when there is a misunderstanding, the caregiver underestimates the importance of a specific value. The exception, “Maintain continuity with the past,” may reflect the caregiver’s own difficulty in letting go of their relative and the relationship they once had together. In general, however, caregivers have a sense of what is important, but not how important certain values and preferences are to their relatives.

### **CAN CONSUMER DIRECTION BE ACHIEVED FOR BOTH CAREGIVERS AND CARE RECEIVERS?**

*“Coming to some understanding of what IS in the best interest of my mother, is the hardest part.”*

—48-year-old daughter caring for her mother who has Alzheimer’s disease

Autonomy, control, and self-determination are important to most everyone regardless of age or physical or cognitive ability. Consumer direction is much more than having the freedom to choose one’s worker or assistant (Scala & Nerney, 2000). One of the main principles of CD is that informed consumers make decisions about their care or, in the case of family caregiving, the care of their relatives. In most instances, family caregivers are able to make decisions about the care of their impaired relatives. But can persons with cognitive impairments make decisions and voice their own preferences? Mounting evidence suggests that

persons with mild to moderate levels of cognitive impairment are able to answer questions with a high degree of reliability and accuracy. These mild to moderately impaired care receivers possess sufficient capacity to state specific preferences, provide valid responses to questions about their demographics and their own involvement in everyday living, make care-related decisions, and express values and wishes regarding care they are receiving or would need in the future (Feinberg & Whitlatch, 2001). This research suggests that it may be useful for families and practitioners to incorporate a structured values assessment as part of interventions to improve education and enhance communication between care receivers and family caregivers around the issues of daily-care preferences.

Drawing upon these findings, Whitlatch and Zarit (2003, November) are designing and evaluating an intervention to help families (i.e., the caregiver and care receiver) who are experiencing the early stages of dementia or other cognitive impairment. The goals of this intervention study, funded by the National Family Caregiver Support Program, are to develop positive communication patterns between the caregiver and the care receiver; increase knowledge and understanding of available services, preferences for care, and care values; and increase the care receiver's active participation in his or her care plan. In turn, caregivers and care receivers are expected to experience improved well-being, self-esteem, and an increased sense of self-efficacy in managing the consequences of cognitive impairment. This dyadic intervention is one of the first to embrace the concepts of consumer direction for both the caregiver and the care receiver.

The number of consumer-directed programs and interventions that serve caregivers and care receivers is slowly increasing. The range and scope of these programs vary greatly according to funding source, financial resources, population served, and organizational capacity. As more consumer-directed programs are developed and implemented, it is important to remember a few key issues:

1. Not all consumers want or will use consumer-driven service options.
2. Empowering the caregiver can have a tremendous impact, either negative or positive, on the care receiver.
3. Empowering the care receiver can have a tremendous impact, either negative or positive, on the caregiver.
4. No single consumer-directed model will be useful in all settings, thus flexible designs in consumer-directed care are crucial.
5. Consumer-directed programs must be thoroughly evaluated, modified, and re-evaluated if they are to be efficient and effective.

6. The results of program evaluations must be disseminated widely to ensure the continuation and replication of effective consumer-directed programs.

Consideration of these six issues is vital to the success and continuation of consumer-directed programs. Public policies that acknowledge persons with cognitive impairment *and* family caregivers as legitimate *consumers* of long-term care will provide additional support to the development of effective and innovative consumer-directed services. Moreover, increased understanding of the preferences of the person with cognitive or physical impairment and the needs of the family caregiver will improve the decision-making process, lead to more informed decisions, and reduce the strain on family caregivers and associated health costs. It is, after all, family caregivers, who are today and will continue to be in the foreseeable future, the major providers of long-term care.

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### REFERENCES

- Advisory Panel on Alzheimer's Disease. (1992). *Third report of the advisory panel on Alzheimer's disease, 1991*. DHHS Pub. No. (ADM)92-1917. Washington, DC: Superintendent of Documents, U.S. Government Printing Office.
- Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQOL). *The Gerontologist, 39*, 25–35.
- Cohen, D. (1991). The subjective experience of Alzheimer's disease. The anatomy of an illness as perceived by patients and families. *American Journal of Alzheimer's Care and Related Disorders and Research, 6*, 6–11.
- Cohen, D., & Eisdorfer, C. (1986). *The loss of self*. New York: Norton.
- Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *The Gerontologist, 33*, 205–211.

- Degenholtz, H., Kane, R. A., & Kivnick, H. Q. (1997). Care-related preferences and values of elderly community-based long term care consumers: Can care managers learn what's important to clients? *The Gerontologist*, 37, 767-776.
- DeJong, G., Batavia, A. I., & McKnew, L. B. (1992). The independent living model of personal assistance in national long-term care policy. *Generations*, 16, 89-95.
- Downs, M. (1997). Progress report: The emergence of the person in dementia research. *Aging and Society*, 17, 597-604.
- Eustis, N. (2000). Consumer-directed long-term care services: Evolving perspectives and alliances. *Generations*, 24(3), 10-15.
- Family Caregiver Alliance. (1999). *Prevalence of the major causes of adult-onset brain impairment in the United States*. San Francisco, CA: Family Caregiver Alliance.
- Feasey, J. C. (1996). *Health outcomes for older people: Questions for the coming decade*. Washington, DC: National Academy Press.
- Feinberg, L. F., & Whitlatch, C. J. (1998). Family caregivers and in-home respite options: The consumer-directed versus agency-based experience. *Journal of Gerontological Social Work*, 30(3), 9-28.
- Feinberg, L. F., & Whitlatch, C. J. (2001). Are persons with cognitive impairment able to state consistent choices? *The Gerontologist*, 41, 374-362.
- Gerety, M. B., Chiodo, L. K., Kanten, D. N., Tuley, M. R., & Cornell, J. E. (1993). Medical treatment preferences of nursing home residents: Relationship to function and concordance with surrogate decision makers. *Journal of the American Geriatrics Society*, 41, 953-960.
- Hibbard, J. H., Slovic, P. & Jewett, J. J. (1997). Informing consumer decisions in health care: Implications from decision-making research. *Milbank Quarterly*, 75, 395-414.
- High, D. M. (1988). All in the family: Extended autonomy and expectations in surrogate health care decision making. *The Gerontologist*, 28(Suppl.), 46-51.
- Kane, R. (1995). Decision making, care plans and life plans. In L. B. McCullough & N. L. Wilson (Eds.), *Long term care decisions: Ethical and conceptual dimensions*. Baltimore, MD: The Johns Hopkins Press.
- Kane, R., & Degenholtz, H. (1997). Assessing values and preferences: Should we, can we? *Generations*, 21, 19-21.
- Kapp, M. B. (1996). Enhancing autonomy and choice in selecting and directing long-term care services. *The Elder Law Journal*, 4, 55-97.
- Kapp, M. B., & Mossman, D. (1996). Measuring decisional capacity: Cautions on the construction of a capacitor. *Psychology, Public Health and the Law*, 2, 73-95.
- Kitwood, T. (1997). The experience of dementia. *Aging and Mental Health*, 1, 13-22.
- Kitwood, T., & Benson, S. (1995). *The new culture of dementia care*. London: Hawker Publications.
- Logsdon, R., & Teri, L. (1996, November). *Assessment of quality of life, pleasant events, and depression in Alzheimer's disease outpatients*. Paper

- presented at the annual meeting of the Gerontological Society of America, Washington, DC.
- Louis Harris and Associates. (1982). Views of informed consent and decision-making: Parallel surveys of physicians and the public. In President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Making health care decisions: A report on the ethical and legal implications of informed consent in the patient practitioner relationship*. Washington, DC: U.S. Government Printing Office.
- McCullough, L. B., Wilson, N. L., Teasdale, T. T., Kolpakchi, A. L., & Skelly, J. R. (1993). Mapping personal, familial and professional values in long term care decisions. *The Gerontologist*, 33, 324-332.
- McHorney, C. A. (1996). Measuring and monitoring general health status in elderly persons: Practical and methodological issues in using the SF-36 Health Survey. *The Gerontologist*, 36, 571-583.
- National Council on the Aging. (1996, July). *Principles of consumer-directed home and community-based services*. Washington, DC: National Institute on Consumer-Directed Long Term Care Services, National Council on the Aging.
- Ogletree, T. W. (1995). Values and valuation. In W. T. Reich (Ed.), *Encyclopedia of bioethics: Revised edition* (Vol. 5, pp. 2515-2520), New York: MacMillan.
- Parmlee, P. A., Lawton, M. P., & Katz, I. R. (1989). Psychometric properties of the Geriatric Depression Scale among the institutionalized aged. *Psychological Assessment*, 1, 331-338.
- Salmon, J.R., & Polivka, L. (2000). Study shows link between control and consumer satisfaction. *Consumer Choice News*, 4(4), 4, 6, 8.
- Sansone, P., Schmitt, R. L., & Nichols, J. N. (1996). *The right to choose: Capacity study of demented residents in nursing homes*. New York, NY: Frances Schervier Home and Hospital.
- Scala, M.A., & Nerney, T. (2000). People first: The consumers in consumer direction. *Generations*, 24(3), 55-59.
- Sciegaj, M. (2001) Elder preferences for consumer direction. Paper presented at Consumer Voice and Choice, Scripps Gerontology Center, Fourth Conference on Long-Term Care. October 18, 2001, Columbus Ohio.
- Sciegaj, M., Capitman, J.A., & Kyriacou, C.K. (2004). Consumer-directed community care: Race/ethnicity and individual differences in preferences for control. *The Gerontologist*, 44(4), 489-499.
- Simon-Rusinowitz, L., Bochniak, A. M., Mahoney, K. J., Marks, L. N., & Hecht, D. (2000). Implementation issues for consumer-directed programs: A survey of policy experts. *Generations*, 24(3), 34-40.
- Simon-Rusinowitz, L., & Hofland, B. F. (1993). Adopting a disability approach to home care services for older adults. *The Gerontologist*, 33, 159-167.
- Simon-Rusinowitz, L., Mahoney, K., Desmond, S., Shoop, D., Squillace, M., & Fay, R. (1997). Determining consumer preferences for a cash option: Arkansas survey results. *Health Care Financing Review*, 19(2), 87.
- Stewart, A., Sherbourne, C., & Brod, M. (1996). Measuring health-related quality of life in older and demented populations. In B. Spilker (Ed.), *Quality of*

- life and pharmaeconomics in clinical trials: Second edition* (pp. 819–829). Philadelphia: Lippincott-Rasen.
- Whitlatch, C. J. (1999, November). The impact of culture on healthcare decision-making for caregiving families. In E. E. MaloneBeach & C. J. Whitlatch (Organizers). *Culture and caregiving in African American families*. Symposium conducted at the Annual Meeting of the Gerontological Society of America, San Francisco.
- Whitlatch, C. J., Feinberg, L. F., & Tucke, S. T. (in press). Accuracy and consistency of responses from persons with dementia. *Dementia: The International Journal of Social Research and Practice*.
- Whitlatch, C. J., & Zarit, S. (2003, November). *Research and interventions with family caregivers and persons with dementia: Respecting both voices*. Symposium presented at the Annual Meeting of the Gerontological Society of America, San Diego, CA.
- Wilson, N. L. (1995). Long-term care in the United States: An overview of the current system. In L. B. McCullough and N. L. Wilson (Eds.), *Long-term care decisions: Ethical and conceptual dimensions*. Baltimore: The Johns Hopkins University Press.
- Woods, B. (1999). The person in dementia care. *Generations*, 23, 35–39.
- Yale, R. (1999). Support groups and other services for individuals with early-stage Alzheimer's disease. *Generations*, 23, 57–61.
- Young, R. (1994). Elders, families and illness. *Journal of Aging Studies*, 8, 115.
- Zarit, S. H., & Goodman, C. R. (1990). Decision making and dementia. *The American Journal of Alzheimer's Care and Related Disorders and Research*, September–October, 22–28.

## RECOMMENDED RESOURCES ON CONSUMER DIRECTION

- National Council on the Aging. (1996, July). *Principles of consumer-directed home and community-based services*. Washington, DC: National Institute on Consumer-Directed Long Term Care Services, National Council on the Aging.
- The entire issue of the journal *Generations* (Volume 24, no. 3, Fall 2000) is devoted to a variety of topics related to consumer direction. This volume is titled "Consumer Direction in Long-Term Care" and is a publication of the American Society on Aging, 833 Market Street, San Francisco CA 94103-1824, [www.asaging.org](http://www.asaging.org).
- For further information on the Cash and Counseling Demonstration and Evaluation contact the University of Maryland Center on Aging, [www.inform.umd.edu/aging](http://www.inform.umd.edu/aging).
- Doty, P., Kasper, J., & Litvak, S. (1996). Consumer directed models of personal care: Lessons from Medicaid. *The Milbank Quarterly*, 74, 377–409.

Commonwealth Fund Commission on Elderly Living Alone. (1991). *The importance of choice in Medicaid home care programs: Maryland, Michigan, and Texas*. New York: Louis Harris and Associates.

For further information on California's statewide system of consumer directed Caregiver Resource Centers contact Lynn Friss Feinberg, Deputy Director, National Center on Caregiving, Family Caregiver Alliance, 690 Market Street, Suite 600, San Francisco, CA 94108, [www.caregiver.org](http://www.caregiver.org).