Consumer Voice and Choice in Long-Term Care

Edited by

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SPRINGER / PUBLISHING COMPANY
NEW YORK

Scrutinizing Familial Care in Consumer-Directed Long-Term Care Programs:

Implications for Theory and Research

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Among the most important and provocative public policy changes affecting long-term care in the United States in recent years is that of consumer-directed care (CDC) (e.g., Benjamin, 2001; Doty, Kasper, & Litvak, 1996; Kunkel, Applebaum, & Nelson, 2003–2004). What distinguishes CDC is an insistence that care recipients' preferences be placed at the model's center. Ascribing decision-making authority to people who have traditionally been seen as passive (if grateful) objects of medical/professional control involves a fundamental shift in perspective, for researchers and practitioners alike (Yamada, 2001).

In this chapter, I reflect, in a constructively critical way, on the burgeoning literature on CDC for older adults. My analysis is informed by a *critical gerontology* perspective (e.g., Estes & Linkins, 2000; Holstein & Minkler, 2003; Luborsky & Sankar, 1996). My focus is on the implications of *familial* caregiving within CDC programs, which has proven to be a significant precondition for their expansion as a policy option. Despite the centrality of familial care to the expansion of CDC, the extensive literature on this approach has not fully explored its implications. Despite the culturally and politically normative aura surrounding familial

care, we need to address the question, as Strawbridge and Wallhagen did (1992): whether "all in the family is always best."

I discuss four interrelated themes that are important for understanding and assessing CDC in the future: (1) structural labor problems in paid caregiving, (2) the tendency to idealize familial caregiving compared to paid care in the public sphere, (3) neglect of class and gender stratification in the provision of care work, and (4) distortions contained in the market metaphor in which consumer-directed care is embedded.

SITUATING AND REFLECTING ON CDC RESEARCH

In principle, everyone advocates wider discretion for disabled people regarding the nature and scheduling of care. However, questions regarding who specifically provides care, and the extent to which programs and policies such as CDC address the broader public policy context and supports surrounding familial care warrant more attention. A large body of prior theory and research strongly suggests that, without fundamental improvements in the provision of *extra-familial* care, in the public sphere, demands placed on familial caregiving will intensify, even as demographic trends reveal the inadequacy of this model as a long-term solution to challenges of societal aging. Furthermore, overreliance on familial care will inevitably exacerbate class and gender inequity and divert attention from structural reforms in the caring labor force which are central to overarching policy goals (see Strawbridge & Wallhagen 1992). I agree with Keigher (1999, p. 206), who writes, "The key public policy question should be how well [CDC] arrangements serve all sectors of communities in need, including the providers of care." Meeting this goal will require critical reflection on select implications of CDC—for familial and non-kin caregivers alike. The latter group has not been a central focus of the literature on CDC. However, my experiences as a paid caregiver[1] and a sociologist of work and occupations have sensitized me to issues of non-kin care. In turn, my assessment of the literature on CDC is less sanguine than is typical of authors in this volume.

Most prior research on CDC—by evaluation researchers and advocates of community-based care options for older adults—has been strongly positive about its benefits for those with chronic disabilities (e.g.,

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[1] In the late 1980s, I worked for some 18 months as a paid caregiver in a residential care facility for older adults with cognitive illnesses; I followed this experience with nearly 2 years of ethnographic research in this setting, including observation and interviews with paid staff and residents' family members (see Wellin & Jaffe, 2004).

Doty, 2004; Eckert, San Antonio, & Siegel, 2001; Keigher, 1999; Yamada, 2001). To achieve greater control and flexibility in both the manner and scheduling of their care, care recipients or "consumers" in such programs are permitted to act as employers, ostensibly free to hire and fire caregivers. Though hiring familial caregivers is but one among a wider set of options available to participants, in fact doing so has proven to be the most common arrangement.[2] This finding is the point of departure for my argument. As employers, consumers are able to channel public funds (e.g., through Medicaid waivers granted to states or local tax levy programs) to care providers, an arrangement designed to shift control from agency personnel to care recipients. CDC clients have, in fact, been shown to perceive greater control, autonomy, flexibility, and satisfaction in daily care arrangements than has generally been true either in institutional care or in conventional agency-governed programs employing home health aides. Care recipients, policy advocates, and academics alike celebrate these findings.

What is equally clear is that CDC programs, in various forms, are here to stay. As Benjamin (2001) points out, several conditions have converged to reinforce this policy agenda: effective advocacy by disabled adults of all ages, consumer movements challenging the dominance of medical personnel and controls, concerns over dramatic increases in the demands and costs of long-term care, the Supreme Court's recent "Olmstead" decision mandating "least restrictive" community care options for the disabled,[3] and a serious shortage of direct care workers—all have contributed to the momentum among governmental policymakers and private foundations to advance and assess CDC initiatives. Also, CDC models resonate with prevailing political realities and cultural norms in the United States: these include, respectively, the contraction and devolution of welfare state policies and filial (read *women's*) obligations to assume, to the extent possible, responsibility for elder care.

In the past decade or so, the CDC model has expanded beyond its historical connections with younger disabled persons and has been implemented and evaluated in programs serving older adults. But as this model becomes more firmly established, it is essential that researchers and

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[2] I use the term familial to refer to family members and friends, with whom recipients may enjoy kin-like relations (see Bould, 1993.)

[3] Passed on 1999, the Supreme Court's Olmstead decision mandates that "states are required to place persons with ... disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with ... disabilities."

advocates for long-term care options examine CDC from various theoretical and substantive angles. Yamada (2001) is helpful in clarifying our need to consider implications of CDC for particular groups of *stakeholders*: these include care recipients, familial and other caregivers, professionals such as social workers who are central in coordinating agency-based care, government/policy actors, and even researchers. Inevitably there are tradeoffs in social policies, regarding costs and benefits for particular groups. Thus an important part of the future agenda for CDC researchers will be to examine such tradeoffs, in an attempt to reconcile tensions and better integrate the model in the overall system of long-term care.

Taking a step in this direction, in this chapter I develop several areas of critique (listed later) that address the origins, limitations, and even the language/discourse of CDC in prior literature.[4] My central focus is the impact of CDC on family caregivers, with an eye toward issues of gender equity and the larger context of public support for caregiving. In addition to developing several themes that, in my view, invite caution in our adoption of CDC, I address underlying problems regarding its relation to efforts that address enduring structural problems in paid caregiving. My argument is that CDC and efforts to enhance the system of non-familial care are best seen as *complementary, rather than competing*, policy agendas.

APPLYING A CRITICAL GERONTOLOGY PERSPECTIVE

My analysis is informed by the *critical gerontology perspective* (e.g., Estes & Linkins, 2000; Holstein & Minkler, 2004; Luborsky & Sankar, 1996). This approach proceeds from concrete research topics and terminology in our field—which, as with CDC, are often specialized and technical—and opens them up to reflective scrutiny. Critical gerontology utilizes such established theoretical perspectives as political economy and feminist theory, "whose standpoints can unsettle familiar and conventional ways of thinking by revealing their often-unrecognized underlying values and consequences" (Holstein & Minkler, 2004, p. 788). Luborsky & Sankar (1996, pp. 99–100) write that, having defined and contextualized—whether culturally or historically—a particular topic, the goal of critical gerontology is to reveal...gaps and limitations in the concept/problem

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[4] We should reflect carefully on the connotations and implications of terminology in public policy discourse; as Lakoff and Johnson (1980, pp. 10–13) argue, metaphors have the power either to "highlight or hide" important dimensions of public issues. In concluding the chapter I return to a discussion of the uses and problems of this metaphor for CDC research.

formulation's ability to explain the phenomena it focuses on, and other problems it does not highlight."

A critical gerontology approach, then, aims not to refute, but to extend or reframe questions and findings in a topical area, better to inform research and practice. Fraser and Gordon (1997, p. 619) are correct in writing that "such a critique is not merely negative. By questioning the terms in which social problems are named, we expand the collective capacity to imagine solutions." By emphasizing what I see as problematic issues in CDC, I hope to sharpen that "imagination" and to use CDC as a strategic site to consider issues of general relevance to social research on aging, family, and caregiving.

As a policy initiative affecting the lives of extremely vulnerable people, and given the inadequacies and indignities of institutionally based long-term care, CDC provokes strong reactions; this applies to researchers and policy analysts, as well as to clients, their friends and family members, and occupational groups such as case managers, for whom the implications of CDC are complex and far-reaching. Equally important is the magnitude of the public–private partnership that has coalesced around CDC: the National Council on Aging, the U.S. Department of Health and Human Services, the Robert Wood Johnson Foundation, and the Centers for Medicare and Medicaid Services, academic research institutes in several states—all have invested financial and staff resources in support of CDC pilot programs and their evaluation. All of these groups, along with the policymakers and government entities involved in CDC, are stakeholders with distinctive interests and perspectives on the policy. As such, they have commitments that inevitably shape how they define CDC—both as a public policy and as an object of social research.

Like any analyst, my view of CDC is similarly filtered through particular disciplinary and topical concerns. Jaffe and Miller (1994) point out that the social experiences, interests, and concepts we bring to studying a particular problem create *positionality*—distinct angles of vision that shape how we assess research questions and answers. This argument echoes Becker's important earlier (1970) essay, "Whose Side Are We On?" His point was partly that there are *always* value positions in our research, and that we should strive to make them—and the scope of our inquiry—clear, and thus less apt to cloud or distort the inferences we make. He argues further that charges of bias are especially likely if/when our research challenges "hierarchies of credibility" (p. 126) by advocating for groups that have been marginal or discredited. Ironically, CDC researchers' strong and legitimate identification with care recipients may obscure the broader web of ties and consequences affecting those on whom "consumers" depend for expanded care options.

CDC, DISABILITY, AND CHALLENGES OF LATE LIFE

A review by Ungerson (2000) shows that CDC is but one among a spectrum of policies—many in Western Europe and the UK—that since the 1970s have allowed public cash allowances to support familial caregiving. She argues that, over time, the primary goals and constituencies of such policies have changed: an early focus in the 1970s on addressing the poverty that often accompanies disability, shifted in the 1980s to efforts to compensate the value and gendered nature of caring work. More recently, in the 1990s, advocacy for CDC has centered on disabled people's entitlement to dignity, autonomy, and control over the care they receive. This current framing of the policy in the United States has de-emphasized problems of poverty and gender equity (Hess, 1985); issues of familial norms and obligations in CDC, if raised at all, have generally been portrayed as benign (i.e., as conditions that stimulate and enhance the quality of care). Contractions in welfare state policies and fiscal constraints, though implicit, are simply assumed in current policy and academic discourse.

In the United States, the roots of CDC can be traced to the Independent Living Movement (ILM) of the 1960s and 1970s, which was driven by demands by younger disabled adults for maximal autonomy in their everyday lives (Benjamin & Matthias, 2001; Eustis, 2000). In contrast, many CDC pilot programs currently being carried out and evaluated across the United States involve disabled *older* adults, including those with multiple chronic conditions and even cognitive illnesses such as Alzheimer's disease. Such conditions, and the dependence they engender, are difficult to square with assumptions about autonomy and self-determination that are central to the philosophy and administration of CDC.[5] Understanding better the implications of life-course differences is important in how we conceptualize and administer CDC programs. Although the ILM aimed to achieve autonomy for disabled adults both *in* the community and *from* their family networks, CDC for elders has proved to be highly dependent on family care. Given the qualms—both cultural and personal—many elders have, about "being a burden" to one's children, and the intensification of work demands facing men and women alike in the United States, this is a provocative finding. Whether elders' preference for kin care is a product of general assumptions about filial obligation, particular care demands, negative prior experience with paid care, or of a tendency to concentrate one's circle of intimate others in late life (see Carstensen, 1995) are empirical questions that deserve careful attention from researchers.

[5] See Collopy (1988) for an important conceptual taxonomy of autonomy.

Furthermore, there are major differences in health status and in the *trajectory* of disability among groups at different stages of the life course. The health status of younger disabled adults, for example, those who are employed but wheelchair bound, is often fairly stable. Typically it is characterized by a "plateau" of functional adaptation in which maintenance of independence at home is a basis for pursuing goals in education, work, and recreation (Benjamin, 2001, p. 86). In contrast, health trajectories of older adults are more likely to be volatile or even progressive. A fruitful theme in the future research agenda regarding this care model will be to explore, theoretically and empirically, the extent to which and how life-stage and life-course dynamics (e.g., the nature and quality of social roles and relations that are salient for the disabled person) shape the experience and optimal administration of CDC programs.[6]

From the standpoint of social service administration, CDC challenges the traditionally hierarchical, professionally dominated *medical model* in aging services (e.g., Morgan & Kunkel, 2001, pp. 346–349; see Conrad 1987). Inadequate fiscal, regulatory, and evaluation constraints have also hampered the quality of care, including that provided in the community through the "home health" industry (Applebaum & Phillips, 1990; Estes & Close, 1998). Thus, implementing CDC has required personnel such as case managers and social workers to alter their role and mission, along with the regulatory constraints they have regarded as protective of client safety and quality of care. In the past it was assumed (e.g., Benjamin, 2001) that the CDC model was limited in its relevance for older adults because of the demands it imposes on clients to manage employment relations, paperwork, and complicated third-party payment procedures. Also, health and social services for older adults have traditionally been more subject to formal case management and regulatory rules than have those involving younger adults. Such rules, and the web of professional practices that support them, were a major barrier to early CDC pilot programs enacted as part of Medicaid's home and community-based services. Currently, arrangements such as allowing for "authorized representatives" to oversee fiscal management have helped in overcoming these barriers, which in turn has allowed for expanded enrollment.

Research on CDC confirms, however, that the traditional system of rigid standards has not only proved to be inadequate to assure high-quality care and client control but also "[tended] to limit or inhibit client and family caregiver involvement in such critical areas as hiring and firing

[6] Moreover, prior research by Jaffe (1989) on intergenerational home sharing suggests that the perceived success and duration of dyads depends in good part on the extent to which dyad members' respective goals and capacity for independence are in synch.

decisions and the scheduling and day-to-day supervision of aides" (Doty et al., 1996, p. 402). It is clear, then, that participation in CDC is driven not only by attractive "pull" factors (including greater flexibility and freedom in choosing care providers and schedules) but also by factors that "push" people away from agency-based care or that have limited the availability such care. What is important to consider is that complaints about the quality of care that are often targeted at agency-based *providers* could as appropriately be directed at the *regulatory constraints* under which aides have worked. Persuasive research (e.g., Aronson & Neysmith, 1996: Eustis & Fisher, 1991; Karner, 1998; Piercy, 2000) reveals that care recipients and paid providers (no less than family care providers) share many priorities and preferences regarding the meanings of, and conditions necessary for, excellent care. Still, when combined with the poor labor conditions facing paid caregivers, which chronically undermine the quality and continuity of care, these regulatory strictures have placed severe limits on the ability of clients to negotiate and sustain satisfying lives despite disability.

Historically, reluctance to extend CDC and other innovative programs to disabled older people has also reflected deeper cultural barriers. Cohen (1988, p. 25) calls attention to what he terms the "Elderly Mystique," an implicit, paternalistic form of ageism which assumes "that when disability arrives, hope about continued growth, self-realization, and full participation in family and society must be abandoned so that all energy can be directed to avoiding the ultimate defeat, which is not death, but institutionalization, which is regarded as a living death." These cultural biases compound the regulatory and occupational constraints on the autonomy of older adults with disabilities. So it is not surprising that CDC researchers have concentrated on such constraints, more than they have on broader issues and implications surrounding the policy.

Established Foci of Applied Research on CDC

Research on CDC has thus far emphasized applied, policy-relevant questions, such as how we might best plan, implement, and evaluate consumer-directed care programs. Inasmuch as such programs operate currently in more than half the states in the United States, the importance of generating and disseminating evaluation research is clear.

At the conference in 2001, which was a forum for several of the chapters in this book, and generally in the policy literature, CDC has been examined through the prism of professional, administrative, and analytic/research questions. Among them are the following. How are the roles of conventional agency personnel such as case managers likely to change in CDC programs, and how can we overcome occupational barriers to its implementation? When and how should we incorporate CDC programs

into long-term care planning? What kind of information is essential for assessing the appropriateness of particular enrollees for participation in CDC? How should we revise our quality indicators for CDC to include consumer perspectives? How can we translate such data on quality into program administration? Can we document significant improvements in consumers' satisfaction with care, in CDC versus agency-based arrangements? As my co-authors in this book attest, answers to these questions have important and wide-ranging implications, particularly for stakeholders directly involved in administering or evaluating CDC programs. But, broader scrutiny of this policy calls for a mode of analysis that extends such questions and connects them with related streams of research.

POINTS OF DEPARTURE FOR CRITICAL INQUIRY INTO CDC

Having sketched the larger context of my interest, I explore several of the key assumptions and questions that have been central in researchers' discourse on CDC in recent years. I believe there has been too narrow a focus regarding some questions, and the omission of others, that are central to sociological theory and research in carework. Four interrelated problems I address are:

1. Structural employment/labor problems that afflict paid caregivers and care recipients;
2. A tendency to idealize (in effect if not by intent) familial caregiving in contrast to paid care in the public sphere;
3. Class and gender inequity in the provision of care work, which CDC seems potentially to exploit and to reproduce;
4. Distortions contained in the market metaphor in which consumer-directed care is embedded.

Structural Work Problems That Afflict Paid Caregivers and Care Recipients

The emergence of CDC as a policy option has been driven partly by a looming crisis in the recruitment and retention of paid care workers. This problem has been long in the making; it reflects such large-scale economic and policy conditions as inadequate insurance reimbursement and limits on levels of third-party payments as well as on limited personal resources of elders needing home care (Kane, 1989). More recently, Noelker (2005) and Atchley (1996) are among those who have shown that the pool and stability of the caregiving workforce is woefully inadequate to meet the

needs of an aging society. Atchley (p. 18) reports: "This shortage is projected to reach crisis proportions very soon. Indeed, chronic short-staffing of nursing homes and waiting lists stemming from a shortage of home care workers are a reality in many areas already." Roots of this shortage are laid bare in the U.S. Department of Labor Statistics *Occupational Outlook Handbook*. For example, it is clear to anyone who has had a hospital stay or cared for a family member that such work requires sensitivity and skill. Yet in the labor market, "Personal and Home Care Aides" are defined and compensated according to an instrumental and demeaning image of what constitutes caring work. The *Handbook* reports that:

> [Such aides] help elderly, disabled, and ill persons live in their own homes or in residential facilities instead of in a health facility. Most work with elderly or disabled clients who need more extensive care than family members or friends can provide... They clean clients' houses, do laundry, and change bed linens. Aides may plan meals... shop for food, and cook. Aides also may help clients move from bed, bathe, dress, and groom. Some accompany clients outside the home, serving as a guide and companion.

The report goes on to report an optimistic job outlook for such workers, who numbered more than 400,000 in the year 2000, because of unusually high employment growth in this sector—especially for those entering elder care. On the other hand, we read that recruitment is undermined because "Turnover is high, a reflection of the relatively low skill requirements, low pay, and high emotional demands of the work" (http://www.bls.gov/oco/ocos173.htm).

As of the year 2000, the median hourly earnings of personal and home care aides was $7.50 per hour/$1,200 per month (with visiting home health aides earning a dollar less, and those in residential care facilities somewhat more). More recently (2005), the Service Employees International Union reported that nearly one-fifth of direct care workers they represent, who are single parents, qualify to receive Food Stamps. As Atchley (1996) points out, the problems of low pay are compounded by an absence of health insurance and other employee benefits (which are especially inadequate for *independent* care providers, such as most in CDC) and by an absence of mechanisms that promote continuity of care and other sources of job satisfaction. He concludes, in fact, that "major predictors of job satisfaction include continuous orientation programs that give aides a collective voice and sense of belonging in the employing organization; ongoing training to extend and refine skills in caregiving; and shared decision-making and flexible supervision to address employees various needs" (p. 18; and see Wilner, 2000). Unfortunately, few employers

furnish these benefits, and so chronic problems of turnover and lack of public trust in paid care persist.

This pattern is sadly ironic, in that several researchers (e.g., Aronson & Neysmith, 1996; Foner, 1994; Wellin & Jaffe, 2004) have documented paid caregivers' strong commitment to those for whom they care, and their resourcefulness in circumventing bureaucratic and other barriers to humane caring relationships (see also Eustis & Fisher 1991; Stone, 2000a). Cancian (2000) reviewed research in a range of care settings—including hospitals and nursing homes—with an eye to the provision of paid *emotional care*. In bureaucratic settings, which tend to fragment caring relations into instrumental tasks, such care tends to be invisible or even discouraged; it is rarely acknowledged or compensated as part of the work routine. Yet Cancian (2000, p. 148), too, finds this to be a salient theme among paid caregivers and concludes that "The quality of emotional care... depends in large part on specific characteristics of the organization in which the caregiver works." There is ample evidence, then, that the quality and continuity of paid elder care are influenced by structural work conditions and incentives that have repeatedly been found to operate in occupations that many regard as more "professional" than caregiving.

Although the vast majority—roughly 80%—of care continues to be provided by informal sources (friends and family), the need for a more extensive and better system of public/paid care becomes more urgently apparent over time. As Bengston et al. (2003) show, this is truly a global phenomenon. Falling death and birth rates portend that, in the future, fewer children and extended family members will be available to care for a growing proportion of people over the age of 65 in the United States (Wallace & Estes, 1996). Noelker (2005, p. 2) reports that, by the year 2030, we will see a 6% decrease in the U.S. population ages 18 to 64 and a 27% *increase* in the population ages 85 and over. Her analysis indicates that, "The ratio of potential informal caregivers (family and friends) will decrease by some 40% between now and the year 2030." In addition, decades of research has confirmed that the quality of familial relationships, between disabled people and care providers, is enhanced when the latter are relieved of some of the burden of giving daily instrumental care (e.g., Bowers, 1990; Smith & Bengston, 1979). There is equally wide consensus that, rather than shirk caregiving tasks, informal care workers assume as much of this responsibility as is possible for them.

A large body of evidence leads inescapably to the implication that future policy should ideally support improvements in the quality and stability of paid caregiving (in the private and public sectors), as an essential condition for disabled people and their families. However, although the

extensive literature on CDC has in passing noted the labor crisis in paid care as a condition for the emergence of CDC, rarely has it addressed whether or how this policy helps to address the root causes of that crisis. In the absence of any explicit analysis of what underlies the shortage of staffing, trust, and continuity in paid care arrangements, research celebrating CDC can have the effect of "blaming the victims" (here, paid caregivers) for exploitative labor market conditions and, in turn, creating an invidious comparison between familial and public care provision. To the extent this is true, a potential implication of research on CDC may be a tendency to idealize (in effect if not by intent) family caregiving in contrast to care in the public sphere.[7] My argument is that these *structural* conditions in paid carework must be addressed, irrespective of who provides care and, furthermore, that failure to address such conditions will only increase reliance on kin care.

Ideals and Limitations of Familial Caregiving

The focus of my critique is the prominent role *familial* caregiving plays in existing CDC programs. This pattern is hardly surprising, inasmuch as family members continue to provide the great majority of such care for elders generally. A note on terminology: in the chapter title, I refer to *familial care.* I use this term, rather than "family care," for empirical and conceptual clarity: first, care recipients in CDC programs are generally permitted to pay either relatives (defined by blood or marriage ties), or friends; second, it has long been recognized (e.g., Stack, 1974) that the term *family* often describes informal, reciprocal networks of emotional and material support based on extended as well as "fictive" kinship (Bould, 1993). It is especially understandable that the commitment of poorer people—as most CDC clients are, as indicated by their eligibility for Medicaid—to familial obligations may take precedence over the conventional "rationality" of individual self-interest. Thus, in practical terms one's ability to take advantage of CDC is typically dependent on existing networks of familial support. This reality is hard to reconcile with the more atomistic market/consumer metaphor.

A recent study, based on a nationally representative sample, found that over 90% of community-dwelling elders get some unpaid help from family, and some two-thirds of them rely exclusively on family supports. Doty (2004, p. 3) reports that they receive a weekly average of 75 hours of assistance, of which 60 are estimated to come from family members. Thus,

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[7] Obscuring dynamics of care, and the perspective of the disabled person, in family discourse is distorting, just as Conrad (1987) and others argued was true of the imposition of medical categories on illness experience.

despite the growing need for elder care—and the conflicting demands of work and child care that challenge family caregivers—we continue to provide it largely through private, voluntary efforts. But what of the compelling need for *extra-familial* support?

It is important to point out, then, that CDC programs contain two related but separable components: the first is an increase in the *types and amount of control* the care recipient is granted, regarding the scheduling and provision of care tasks. (In principle, such control can also be exerted over agency-based care providers and would indeed seem to be most necessary in that case, given that agency-employed workers have limited knowledge of care recipient's needs and lack the filial obligation required naturally to adapt care tasks.) The second component in most CDC programs is *expanded freedom to recruit and hire* care providers (termed "workers" by administrative personnel, as opposed to the "consumer" who receives care). The pool of eligible caregivers is expanded in CDC to include not only home-health agencies or freelance care workers, but also one's network of family members and friends. It is conceptually and also empirically important not to conflate these two issues, because consequential dynamics of caregiving, and of the relationships shared by particular care providers and receivers, vary independently.

We have the benefit of many sensitive studies of home care, some focusing on family caregiving (e.g., Abel, 1990; Corbin & Strauss, 1988; Kosberg, 1992), others on professional/paid home care workers (e.g., Karner, 1998; Piercy, 2000; Piercy & Dunkley, 2004; Rivas, 2003). This research offers remarkable consensus in terms of the expressed ideals and criteria, among all concerned, regarding high-quality care: it requires a sensitive blending of instrumental and socioemotional care, with respect, warmth, and a desire to adapt to individual needs and preferences (Wellin & Jaffe, 2004). What is understandably less well studied and understood, however, is the *integration* of paid and familial caregiving, through the auspices of social policy initiatives such as CDC.

Issues of familial care provision have been a recurring, if not a salient, theme in the growing literature on CDC. Others have noted this trend (e.g., Brown & Foster, 2000; Feinberg & Whitlatch 1998; Kunkel et al., 2003–2004), but none to my knowledge has made it the center of attention. Although informal/family support has historically met most elder care needs, increases in women's labor force participation and the general intensification of work hours and demands in the United States are compounding demographic pressures of societal aging that strain family resources (Bengston et al., 2003). Further, the social bases and implications of this reliance on familial support, in a culture that so prizes independence (from family and institutional constraints alike), deserves careful scrutiny

(Strawbridge & Wallhagen, 1992). Also problematic is the stubborn pattern of gender inequality in the distribution of caregiving responsibility. It continues to be true, as Brody (2004) and others document, that women are often *caught in the middle* of conflicting role demands—as workers, carers, and community/volunteer actors. Abel (1990), examining the phenomenon of daughters caring for aging parents, found that the emotional and practical demands of family care can be overwhelming, even in economic circumstances that are more stable and less stressful than is likely to be true for many CDC participants. Pearlin and colleagues (e.g., Pearlin, Pioli, & McLaughlin, 2001) provide a stream of research that persuasively shows that role disruptions, rooted in long-term care demands, has a negative impact on care workers' health status. In turn, a body of earlier research (e.g., Pillemer & Wolf, 1986) warned against and documented the risks of *elder abuse*, as a result of demands placed on family caregivers, and of declining health status among family caregivers, caught between conflicting role demands (Pearlin et al.) or simply subject to *role fatigue* (Goldstein, Regnery, & Wellin, 1981). Necessary gains for disabled adults, of whatever age, should not impose a prohibitive cost for care providers—including those who, as friends or family members, are normatively expected to fulfill this role.

Context and Tradeoffs of Familial Care in CDC

As stated, research has shown that extending CDC to elder care has relied heavily on the involvement of family and friends, both as care providers and as proxies or "authorized representatives" helping to arrange and monitor payment for care. Although clients have the option to hire friends, family members, or independent aides (e.g., though classified ads), a clear majority—from 60% to 80%, depending on the program under review—has in fact chosen to hire those whom they know. The author of a recent review of the *Cash and Counseling* Program (operating in Arkansas, New Jersey, and Florida) reports, further, "the preference for hiring family members was strongest among elders" (Doty, 2004, p. 6). This finding begs the empirical question of whether the CDC option injects a modest cash reward into preexisting familial care arrangements or, on the other hand, provides an incentive that activates new caring relations and arrangements. It is safe in any case to conclude, first, that the viability of consumer-directed care for older adults, especially those with severe physical or cognitive impairments, will depend significantly on the participation of family members; and second, that this participation inevitably imposes tradeoffs for family caregivers regarding how they allocate time, energy, and resources between compelling and competing obligations (Kapp, this

volume). A fuller understanding of the impact of these tradeoffs, and of their consequences for CDC and for larger debates in long-term care policy, requires that researchers contextualize this initiative in the current political/policy environment, and also that we integrate the growing body of CDC research findings with relevant streams of prior research. Among the most relevant are those dealing with caregiver stress/burden, labor conditions and politics in the service economy, family dynamics, and gender inequality.

Class and Gender Inequality in the Provision of Carework

Beyond demographic constraints are fundamental issues of social justice and equality that require improvement in the cultural and economic value we place on caring work (Stone, 2000b). As Glenn (2000, p. 89) argues, "keeping the family as the 'natural' unit for caring relationships helps anchor the gender division of caring labor ... and disguises the material relationships of dependence that undergird the arrangement." This points up another troubling silence, in public advocacy and CDC research, regarding class and gender inequalities. These inequalities shape the lives of participants in myriad ways. Whether they are Medicaid eligible, or become involved through various community-based care programs, participants in CDC are both poor and beset with chronic and/or progressive disabilities. Middle-class and affluent families are increasingly reliant on "subcontracting" care responsibilities for children and for disabled members; they are able to exert substantial control over care arrangements, and to obtain high-quality, reliable care by virtue of their ability to pay (see Hochschild, 2002, pp. 185–223, *passim*). For the poor, the sheer lack of disposable income is but one of a larger set of cumulative disadvantages, which are manifested in old age and shape the normative and practical negotiation of familial care.

In this connection, De-Ortiz (1993) analyzed New York City's Medicaid-funded home attendant program, via the political economy perspective. She argues that "the elderly poor's health conditions, and thus their need for care, must be examined within the context of their labor histories and the poverty they have confronted and endured throughout their lives ... The cumulative effects of poverty, including nutritional deficiency, inadequate housing, and lack of medical care, also affect the health of the elderly and their need for care" (p. 24). She goes on to point out that substandard housing, not to mention such neighborhood factors as safety and access to basic goods and transportation—all contribute to health status and to the ability of people to access and mobilize resources they need to remain independent.

How is this point connected to the operation of CDC? It is axiomatic in the literature in gerontology that one's ability to remain at home and avoid institutionalization is shaped by support networks as much as by health status per se (e.g., Gubrium & Sankar, 1990). Clients' heavy reliance in CDC programs on familial care reflects long-standing relations of reciprocity and extended kin networks most strongly characteristic of poorer people. Middle-class and affluent families stress "human capital" investments and assume autonomy in pursuit of greater earning potential. Poorer workers, however, are often mired in the service or informal economies and thus have more tenuous and more episodic involvement in wage work. Under such conditions, family members are more likely to stay in geographic proximity with one another, and more accustomed to accommodating daily life to the exigencies of survival among the larger group. It is easy (and too common) to romanticize the resilience of such extended family forms, but they often impose serious constraints and "opportunity costs" on members who, in contrast to middle-class norms may see family more as a community of fate (than of choice). To the extent this is true, CDC is a policy that may respond to the needs and preferences of older disabled people, at the cost of longer term quality of life and income security among younger care providers. To the extent this is true, family care is a significant mechanism for the transmission of intergenerational poverty. Of course, it is an empirical question whether and how caregivers are able to balance their demands under CDC with those of work outside the home, however there is suggestive evidence (i.e., a finding that caregivers provide an average of some 8 hours of care per day) that doing so is challenging.

So far, we have said little about the gender dynamics of child care and elder care, so unchanging have the patterns remained (e.g., Brody, 2004; Calasanti & Slevin, 2001, pp. 146–152). Both at home and in the paid caregiving workforce, the predominance of women is taken for granted (excepting male home health aides responsible for handling immobile clients). The recent gains among women in the labor force and professions, and the success of so many as single parents, depend on their ability to afford or share care responsibilities in ways that preserve their viability as wage or salaried workers. Any caregiving policy that rests on women's work in the home—even if modestly paid—is a threat to this progress. Thus, although the rhetoric and research that is supportive of CDC celebrates the *empowerment* of the recipient/consumer, from a feminist angle it may rather appear as a *re-privatization* of care in the home, in line with an ideology of fiscal austerity, and on the shoulders of the very women who are at the highest risk of facing poverty and ill health in their own later years. More, CDC can be seen to be consistent with a larger trend of policy devolution (from the federal to state and local

governments) as noted by Estes and Linkins (2000, pp. 160–162).[8] The importance of ensuring quality of life for care recipients should not obscure attention to macro-level conditions underlying the emergence and ultimate role of CDC as a policy option. To sum up, I have argued that both the demand for and development of CDC have rested on a largely implicit basis of class inequality. Buttressing kin-care via CDC will not by itself either relieve or exacerbate these deeply entrenched patterns. However, there is a potential danger that policy incentives that draw more poor women into kin-care will compound their disadvantage in terms of education and employment, even as it enhances life for those for whom they care. An implication of this argument is that those seeking to expand CDC should, as Stone (2000b) urges, make common cause with related movements to address structural problems in the social status and rewards for care in the workforce,[9] and that theoretical analyses and evaluations of CDC programs need to recognize and address class and gender processes which (through the mechanism of familial care norms) the policy may exploit and reinforce.

Potential Distortions in the Consumer/Market Metaphor

A final critical theme concerns the conceits and potential distortions of the "consumer/market" metaphor with which policy makers and researchers define and discuss CDC. As cultural critic Raymond Williams and others (Best, 1995; Lakoff & Johnson, 1980) have shown, metaphors have social consequences; they shape how we think about and act toward contested social problems. Metaphors are central to how we *typify* social problems, that is, how we categorize and treat them. As Best (p. 9) explains, particular typifications "emphasize some aspects and not others, they promote specific orientations, and they focus on particular causes and advocate particular solutions." As such, the language we use to represent social problems can limit how we perceive their scope, as well as our realm of power to affect them through policy intervention. It should be apparent, based on the discussion thus far, that the consumer/market metaphor is problematic when applied to care decisions in CDC.

Strictly speaking, a *consumer* is defined as an autonomous individual who acquires a product or service in a competitive market. In a founding

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[8] Indeed, a condition of introducing one CDC pilot in Ohio was that it be "revenue neutral"—cost no more than existing programs.

[9] These coalitions must include the growing union movement among care-workers and others in the allied health professions. Delp and Quan (2002) offer an important analysis of how unionization was part of a successful grass-roots strategy to enhance the working conditions and rewards of home care workers in California.

document of cultural studies, *Keywords*, Williams (1976, p. 69 emphasis, in original) notes that the "decline of *customer* used from the 15th century on to describe a buyer or purchaser is significant, in that *customer* had always implied some degree of regular and continuing relationship to a supplier, whereas *consumer* indicates a more abstract figure in a more abstract market." Whereas market transactions are generally impersonal and ephemeral, family ties of reciprocity are embedded in dense emotional and material bonds, stretching across long periods of time (Groger, 1992).

For all these reasons, the consumer/market metaphor seems strained at best when applied to severely disabled people whose only other options are nursing home residency or reliance on agency-employed health aides. *The term is further strained when considering the prevalence of familial care in CDC: both the decision to enter into CDC and the negotiation over care within dyads is profoundly determined by the resources, traditions, and sentimental order of family life (including extended or fictive kin).* The desire, however deeply felt, to promote or maximize dignity and self-determination among the disabled should not thereby create blindness to powerful conditions of their lives and social networks.

Conceptually, the agency of *consumers* is derived from a premise, not of entitlement or material equity, but rather of metaphorical freedom in a market. Robyn Stone (2000, p. 6) suggests that it is important to distinguish between *consumer choice* and *consumer direction*: "With . . . managed care and Medicare (at least in theory) offering a range of plans as well as a fee for service option, the elderly and younger disabled are facing more choices in how they receive their healthcare. . . . Consumer direction, however, focuses specifically on the degree to which people are proactive in making decisions about care, including the hiring and firing of workers and the oversight of services." For most CDC clients, whose limited resources qualify them for Medicaid funding, the range of choices is quite narrow. For them CDC offers choice in the confined but important domain of how and from whom they get care. However, the choice is constrained in the public sphere by virtue of the shortage and instability of "frontline" staff support, and so for most this choice, and the control it aims to gain, can only be exercised in practical terms when family or friends are both available and willing to take part.

So, how well does the consumer metaphor capture these realities of interdependence? In many ways the image of the consumer—of an isolated and autonomous actor in a market—hides as much as it reveals about the social relationships that underlie CDC. The image has the rhetorical and pragmatic virtue of resonating with a larger policy environment that, since the Reagan years, has stressed contraction of the federal welfare state and privatization in the realm of health and social services (Wallace

& Estes, 1996). For advocates of this connotation of consumer control (a group which I am *not* implying includes CDC researchers), the symbolic freedom to take risks and benefits in the marketplace (as in the ongoing debates about the private accounts in Social Security, or of "local control" in economically strapped urban schools [Lewis & Nakagawa, 1995] takes precedence over the traditional paternalism of formal regulation. This faith in markets tends to elide, when it does not oppose, the universalistic and redistributive aims of welfare policies and the recognition of class/gender inequality. Nonetheless, this image of consumerism tends, in effect, to isolate the care recipient from their supportive, familial network, *recasting relations of interdependence into quasi-employment relations. A material expression of this shift is that, in CDC, the care recipient is designated as both employer and client, ostensibly free to hire and fire care providers.* Recasting the disabled person, from a subject of formal and bodily regulation to an active agent directing their care, has both symbolic and practical power. Indeed, this shift is central to claims for why CDC is *empowering* for care recipients.

Nonetheless, I conclude with references to insights that help to convey the potential dangers of distorted metaphors in the present case. First, Riger (1993, p. 279) develops a conceptual critique of *empowerment*. She concludes that, although valuable, the term is suffused with assumptions and values of individualism, "leading potentially to unmitigated competition and conflict among those who are empowered; and . . . a preference for traditionally masculine concepts of mastery, power, and control, over traditionally feminine concerns of communion and cooperation." So, empowerment is problematic not only because it can lead us to focus narrowly and to obscure relational and contextual dynamics (in this case, bearing on caregiving), but also because it can promote—even among familial networks—zero sum competition which may strain the already delicate fabric of families coping with hard times. The other caveat, in closing, I take from the social theorist Ralf Dahrendorf. Analyzing the nature of "life chances" (1979, p. 31), he argues that they are determined by a combination of *options and ligatures* (or, said differently, choices and enabling social ties). These he says can be in an "optimal relation" with one another: "A maximum of options is not by itself a maximum of life chances, nor is a minimum of options the only minimum of life chances. Ligatures without options are oppressive, whereas options without bonds are meaningless." In the transition from pre-modern societies, Dahrendorf argues, one's fate was largely determined by ligatures, by social ties; we enjoyed few choices that were independent of our ascribed community. In light of our investigation of CDC, and of the prominence in such programs of family care provision, one rightly wonders whether the rhetoric of *consumer choice* might obscure a realization of the

continued (and now formally sanctioned and compensated) role of family ties in the future of elder care for less affluent families in the United States.

CONCLUDING REMARKS

I have been struck by the passionate support of CDC by care recipients and scholars. During a conference on CDC several years ago, I attended a panel discussion involving participants who are currently enrolled in CDC programs in Ohio. One could not but be moved by the testimony of people for whom involvement in CDC has allowed greater control and dignity in everyday life, despite serious and chronic illness. According to Cohen (2004), these progressive goals define, or should, what we mean today by quality in long-term care. My earlier work and research in residential care (Wellin & Jaffe, 2002, 2004) has taught me how disabilities can become defining features of interaction and identity for older people, even for those fortunate to live in comparatively privileged material conditions. From this standpoint, placing care recipients at the center of research and policy is a progressive, even radical, shift, and one that is a necessary though not sufficient condition for reform (also see Conrad, 1987).

Any incremental change in long-term care policy, such as CDC, faces a daunting test: it must reconcile legal, ethical, and cost issues, and also seek to preserve the flexibility and humanity of caring relations. As difficult as these challenges are currently, they also entail longer range issues of generational and gender equity (Hess, 1985). Societal aging, combined with low fertility rates and intensifying work demands for women and men, is exposing a pervasive set of problems that have plagued paid caregivers and the quality of paid care; these include the cultural and economic devaluation of paid care work, chronic instability, and turnover in paid care relations, and racial/ethnic and class divisions between care providers and care recipients (Glenn, 1992). We know empirically (e.g., Benjamin, 2001, p. 82; Feinberg & Whitlatch, 1998) that, regardless of age, disabled people share many priorities regarding the care they receive: they value safety, continuity, flexibility, and sensitivity to individual needs and preferences. These qualities are, of course, neither necessarily present in family ties nor absent in paid/agency-based care. But so long as the structural problems of paid caregiving remain unresolved, public distrust will continue and familial care will represent not only a historical norm but also a misguided cultural ideal. Demographic change, however, in conjunction with the "social imperative" to consider the needs and rights of major groups of stakeholders, requires that we address broader problems in the labor market and service economy.

Some readers may think it far-fetched or alarmist to connect CDC with these broader problems. However, CDC presents a prominent focus of current policy attention and, as such, deserves wide-ranging scrutiny from gerontologists and others with a commitment to addressing long-term care needs. While the public spotlight shines, we need to reveal the broader nature of the caregiving challenge. The weight of my critique in this chapter has been skeptical, but not negative, regarding the findings and implications of prior research on CDC. My questions, and the implications I draw, extend those of others, and my concerns about the wider context of CDC in no way diminish those of others who have studied the policy from other vantage points.

In fact, my critical stance cannot resolve profound dilemmas that have arisen with respect to caregiving research and public policy. One of these concerns a contradiction between my position here and other analyses of the use of public dollars to support *child care*. Many researchers (e.g., Oliker, 2000) who share my premises and policy goals decried the end of Aid to Families with Dependent Children (AFDC) and the imposition of work mandates for single mothers instituted as part of the Clinton Administration's welfare "reform." A central point raised by such writers was that it is wrong to deny funding to poor women who choose to devote their energies to caregiving (as we celebrate among more affluent mothers), especially given what has proven to be the limited options that await them as wage workers. More broadly, Schwartz (2002) makes a compelling case that the historical tendency in the United States for federal and state policies to provide lower levels of funding to kin (than non-kin) caregivers reflects a societal devaluation of caring. In seeking to resolve this contradiction, one could argue that parents choose to have children, as adult children cannot choose to have disabled parents; similarly, one could argue that adults' general preference for independence and autonomy should temper our emphasis on any social policy that might infringe on it (for adults of whatever age). However, these positions betray an ad hoc quality, which only underscores the cultural and political complexity of the issues involved. With respect to CDC, I have argued *not* that we remove this as a policy option, rather that for many reasons it should not be the *only* or default option available to disabled older adults and their families.

In the end, all social policies contain and touch multiple realities; each is important and is shaped by contextual factors that make reconciling them all the more difficult. My goal has been to develop lines of inquiry that will reinforce the centrality of CDC in several related areas of theorizing and research in the social sciences. I have explored questions which I feel are crucial to address in the future, but which have been either implicit or tangential in the growing body of applied research in this area.

In the near future, I look forward to adding to empirical knowledge of CDC in my own research, and to the lively debate and clarification that I have tried to promote.

ACKNOWLEDGMENTS

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