

**PRIVATE DILEMMAS OF PUBLIC PROVISION:  
THE FORMATION OF POLITICAL DEMAND FOR STATE ENTITLEMENTS  
TO LONG-TERM CARE**

by

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## CHAPTER 1

### INTRODUCTION

*However well justified such policies might be, the United States will not undertake an expensive expansion of family policies...unless the demand for these changes is mobilized and communicated to government. ... For a new approach to family policy to become a reality, the private dilemmas of contemporary families will need to be translated into political demands.*

—Janet C. Gornick and Marcia K. Meyers (2003, p. 300)

#### I. THE POLITICS OF NEW SOCIAL NEEDS

Contemporary welfare state politics are not what they once were. Since the 1970s, a sharp slowdown in economic growth, the maturation of governmental commitments made during the height of postwar expansion, and a demographic shift toward an aging population have all generated intense budget pressures on advanced welfare states—pressures which show little sign of diminishing in the next few decades (Pierson 2001c). In this context of “permanent austerity” (Pierson 2001a), scholarly attention has turned from the emergence and expansion of the welfare state (Esping-Anderson 1990; Huber, Ragin and Stephens 1993), to the politics of welfare state retrenchment and restructuring (see generally Pierson 2001b). The focus on efforts to preserve and modernize *existing* governmental commitments in the face of global economic austerity has largely overshadowed what is arguably a defining characteristic of contemporary welfare state politics: the emergence of *new* social needs—requiring *expanded* systems of social provision—competing for public attention and resources with “older” or well-established social needs (Esping-Anderson 1999; Pierson 2001c).

Nowhere is this phenomenon more evident than in the new social risks associated with aging populations and dramatic changes in health care provision, household structure, and

women's labor force participation over the last half century. Together, these distinct yet interrelated trends have created what many observers (Garey et al. 2002; Glenn 2000; Harrington 2000) have dubbed a "crisis in care": the demand for care of the young, the old, and the infirm is growing at precisely the same time as the *supply* of private care within the family is substantially contracting. Care provision for society's most vulnerable has historically been understood to be a *family* responsibility—and the responsibility of women in particular (Harrington 2000).<sup>1</sup> But over the course of the last century, increased longevity and changes in the provision of health care have dramatically changed the nature of family caregiving. The population aged 85 and older—who tend to require very high levels of direct care—is currently the fastest growing segment of the older population (Folbre and Nelson 2000; Rubin 2001). In the United States, nearly half of those aged 85 years or older suffer from Alzheimer's disease or a related form of dementia (National Center for Chronic Disease Prevention and Health Promotion 1999). The *level* of care demanded by those suffering from disease or disability has also changed in recent decades with the deinstitutionalization of a wide array of acute care services (Abel 1991). Virtually all countries have observed a trend toward reduced length of stays in hospitals or formal care (Daly 2001b). Because patients are discharged earlier than they were before, they tend to be sicker when they arrive home, and family members are frequently called upon to manage medical technologies, drugs, and decisions about pain or bleeding, that were once considered the exclusive domain of trained medical specialists (Glazer 1988; Koren 1986).

As care for the sick and disabled has shifted increasingly to private households, the ratio of adult caregivers to dependents in the home has declined. Women's large-scale entry into the paid labor force, increasing numbers of single-parent families, a decline in the average household

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<sup>1</sup> Even today, women make up approximately 75% of all unpaid family caregivers (Brody 2004).

size, and the increasing tendency among young people and the elderly to live on their own, have all resulted in fewer available adults in the home to care for children, the elderly, and the ill (Garey et al. 2002; Harrington 2000; Pierson 2001c).

The consequences of these trends for systems of social provision are potentially substantial: as families increasingly need help with social tasks that have historically been carried out “for free” within the household, many states are being called upon to increase social expenditures for care. Government support for care is in fact one of the few areas of social provision in recent decades that has witnessed growth among countries in the Organization for Economic Cooperation and Development (OECD) in the form of new or expanded social welfare initiatives (Daly 1997). Whether caring services are provided through public means—as is the case in the countries of Scandinavia where households have ready access to public child care and elder care<sup>2</sup>—or through private but marketized means—as in the case of most OECD countries which provide a wide variety of transfer payments to subsidize the costs of market-based care (Daly 2001a)—the contemporary problems of care provision are increasingly recognized by welfare states as new social risks requiring adaptations in existing social policy arrangements (Daly 2005; Pierson 2001c).<sup>3</sup>

In the United States, which has long been known for its anemic social welfare system, families have largely been left to their own devices to craft solutions to contemporary care dilemmas (Gornick and Meyers 2003). Commentators who have been following the dramatic transformations in household structure and the gender order (e.g., Daly and Rake 2003; Gornick

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<sup>2</sup> Since 1989, every elderly resident in Denmark is entitled—as a right of citizenship—to public elder care services, including free home help (Meyer 1994).

<sup>3</sup> For an excellent summary of the types of provision offered in European welfare states, and an analysis of their compensatory aim or logic, see Daly and Rake (2003).

and Meyers 2003; Harrington 2000; Stone 2000a), have observed that no matter how well documented the emerging social risks associated with these trends, the United States is unlikely to expand public provision for health or economic security without significant public demand for state intervention. But notably, despite the well-documented effects of contemporary care dilemmas on economic security,<sup>4</sup> gender equity,<sup>5</sup> class equity,<sup>6</sup> and the physical and mental health of family care providers,<sup>7</sup> the American public has shown little appetite for translating their private care dilemmas into political demands for state intervention. Paid time off from work, tax credits, caregiving stipends, state-subsidized home care, respite care, child care, adult day care, and other support services could all dramatically affect the quality of life for family caregivers, but are rarely discussed in public discourse as political priorities. Recent survey research has found that among caregivers for the chronically ill or disabled in the United States, few conceive of their work as a “public” issue involving *rights or entitlements*; indeed many *reject* such a characterization outright (National Family Caregivers Association 2001). Rather than viewing care provision as a political issue, the American public continues to think about care as something that individual families deal with in the privacy of their own homes.

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<sup>4</sup> Caregivers must cope not only with the financial expenses of caregiving, but working caregivers (who now constitute a majority of all caregivers) typically face additional stresses—and costs—relating to missed work and lost job and career opportunities (England and Folbre 1999; Health & Human Services 1998).

<sup>5</sup> See Glenn (2000) and Fraser (1997). If the emotional and physical responsibilities of care provision fall disproportionately on women, so too do the economic costs of caregiving (Meyer 1994; Wabakayashi and Donato 2005).

<sup>6</sup> A growing literature considers the global consequences of the market for paid care as women from poor countries leave their own families to work as care providers in richer countries (Ehrenreich and Hochschild 2002; Hochschild 2003; Hondagneu-Sotelo 2001).

<sup>7</sup> Researchers have linked caregiving stress to substantially increased rates of depression (Poulshock and Deimling 1984), physical health problems (Archbold 1982; Schulz and Beach 1999), and greater alcohol and psychotropic drug use (Alzheimer's Association & National Alliance for Caregiving 1999; George and Gwyther 1986).

Thus, it seems the central question in the American context may not be why the state has not responded to new social demands by expanding social entitlements for care provision, but rather: *why American families have not interpreted their care needs as demands for state entitlements in the first place.* The conventional wisdom in this regard, often cited in debates about health security more broadly, is that the American public's ambivalence toward state intervention is the product of an anti-statist political culture in which citizens hold private property and individual rights sacred, distrust state authority, and generally prefer private solutions to public problems. But even if there is some truth to these claims, it is also the case that the American public strongly supports existing social welfare programs—indeed the proportion of Americans who support Social Security and Medicare continues to hover well above 75%<sup>8</sup>—and for the past half century, large majorities of the population have favored increased government spending on health care (Hacker 1997).

This dissertation argues that the public's reluctance to view care struggles as public problems derives instead from the uncertain new terrain in which Americans find themselves: caught between deeply held, and longstanding beliefs about family responsibilities for care on the one hand, and shifting demographic, economic, and social realities on the other, the American public has not arrived at any consensus about whether, or to what extent, the state should bear responsibility for the contemporary costs or provision of care. Even in political cultures far more amenable to social protectionism, the rapid changes in family composition and women's employment have produced social tensions over the appropriate role of the state in care provision (Daly and Rake 2003). Claims for new social entitlements, in other words, do not

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<sup>8</sup> A Harris Poll conducted in November 2005 found that 76 percent of adults surveyed supported both Medicare and Social Security. A rigorous social scientific survey conducted in the early 1990s found support for both programs to be over 90 percent (Cook and Barrett 1992).

emerge whole cloth in response to new social conditions; they are the product of shifting norms and beliefs about the interface between family, market, and state. Thus, to understand how new social conditions translate into political demands for new social policy arrangements, we need to understand transformations in *political consciousness* as a critical intervening variable.

In this dissertation, I analyze the development of political consciousness among Americans caring for adult family members with dementia, cancer, and similar chronic diseases. Families in the United States provide as much as 80 percent of the care for the chronically ill and disabled (O'Brien and Elias 2004). As the pool for unpaid family caregivers has contracted in this country, the cost of *purchasing* caregiving services—i.e., in-home supportive services, adult day care, or nursing home care—has escalated sharply.<sup>9</sup> Health insurance policies generally do not cover long-term care expenses at all, and long-term care insurance has proven to be an unreliable, and hence substantially underutilized market (Meyer 2005). Medicare provides acute care coverage for most of the nation's elderly, but very little assistance for patients with chronic illnesses, and Medicaid, a means-tested health care program, mainly provides long-term care assistance for the very poor. Thus, with little public assistance and few market alternatives, family caregivers for chronically ill adults represent an ideal group for examining how ordinary citizens understand—and respond to—new economic and health security threats in their everyday lives. Tracing how family caregivers navigate between traditional conceptions and new realities of family life, I examine how their experiences with caregiving shape their expectations for state intervention. More specifically, I ask: *under what conditions do family caregivers challenge norms about the private responsibility for family care and reconceptualize*

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<sup>9</sup> The average annual cost of a private room in a nursing home in the United States in 2004 was just over \$74,000, up 5.7% from just one year ago. The hourly cost of home health care is on average \$19 per hour, up 5.5% from 2004. The cost of companion or personal care is marginally less, at \$17/hr. Statistics are from the 2005 Metlife Mature Market Institute.

*care provision as a community or social responsibility?* The answer to this question, I maintain, is critical to explaining the absence of political demand for new social entitlements to care.

## II. *THE MULTIPLE DIMENSIONS OF OPPOSITIONAL CONSCIOUSNESS*

In this dissertation, I draw on the concept of “political consciousness” to elaborate and deconstruct the much more ambiguous term, “political demand.” Political consciousness refers to the constellation of principles, beliefs, and understandings about the world that shape how individuals choose to advance their interests or resolve problems in their everyday lives.<sup>10</sup> Here I build on the work of Jane Mansbridge and Aldon Morris (2001), among others, who have observed that we develop particular forms of political consciousness at specific historical moments as certain political opportunities, ideational and institutional resources become available. In this sense, political consciousness is not a static or stable entity—it is not a quality one either “has” or doesn’t “have”—but is continually developed in concrete social action (see also Ewick and Silbey 1998). Although political consciousness from this perspective is neither fixed nor stable, it nevertheless has “shape and pattern” (Ewick and Silbey 1992; Sewell 1992). In any given time or place, there are only a limited number of culturally available interpretations for assigning meaning to events or social conditions (Swidler 1986).

With respect to political consciousness, the range of culturally available interpretations can be thought of as a *continuum*: at one end of the continuum are interpretations of social conditions and experiences that reflect and reinforce the status quo—what I refer to, following Aldon Morris (1992), as *hegemonic political consciousness*. Social norms and institutions in

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<sup>10</sup> This conceptualization is based loosely on Aldon Morris’s (1992, p. 362-63) definition of political consciousness as comprising “those cultural beliefs and ideological expressions that are utilized for the realization and maintenance of group interests.”

this view have a taken-for-granted quality, an inevitability or naturalness that leads to acceptance, rather than critique of one's circumstances. As one moves across the spectrum of political consciousness, becoming more critical of existing social arrangements, one can be said to develop an increasingly *oppositional consciousness* (Mansbridge and Morris 2001).

Social movement scholars have identified at least four analytically distinct dimensions of oppositional consciousness that are widely understood to be necessary, but insufficient, conditions for collective or political action (see Mansbridge and Morris 2001). First, a *minimal* sense of oppositional consciousness must include a sense of *collective identity* (see generally Hunt and Benford 2004; Polletta and Jasper 2001)—a perception of commonality with others experiencing similar social conditions, and a way of connecting one's "personal troubles of milieu" to "public issues of social structure" (Mills 1959, p.8). Second, oppositional consciousness must include a sense of *injustice*, a perception of one's social conditions as *unfair* or *injurious* rather than "unfortunate but perhaps tolerable" (Snow and Benford 1992, p. 173; see also Felstiner, Abel and Sarat 1980-81). Third, a more fully-developed oppositional consciousness must incorporate an *ideology* (Mansbridge 2001), a well-worked out, internally coherent set of ideas and beliefs that links understandings of how the world works with values and normative principles relevant to promoting or resisting social change (Oliver and Johnston 2000). Finally, a "mature"—or fully developed—oppositional consciousness would include a sense of *political efficacy*—a belief in one's capacity to change the terms and conditions of one's life by participating in collective action (Gamson 1992b; Klandermans 1984; McAdam 1982).

The concept of oppositional consciousness provides a useful way of more closely interrogating the multiple dimensions involved in the construction of what political theorists (e.g., Gornick and Meyers 2003) sometimes refer to ambiguously as "political demand." It is

important to emphasize that the development of oppositional consciousness can occur unevenly, with some aspects developing independently of the others (Mansbridge 2001). Thus, it is possible, for example, to interpret one's circumstances as unfair without explicitly identifying with a particular group or collectivity of similarly situated people. And while political action does not necessarily require a fully-developed oppositional consciousness, the likelihood of such action is generally viewed as greater among populations with a relatively more mature political consciousness.

Each of the empirical chapters in this dissertation employs one of these four dimensions of oppositional consciousness to elaborate the social conditions that impede or promote oppositional interpretations of care provision. Together, they seek to identify how the highly individualized, private dilemmas of contemporary care provision come to be understood as shared, or collective grievances that not only require public remediation, but that motivate families to demand new social entitlements for long-term care as a political priority.

Thus, in Chapter 2, I ask: *what role does collective identity play in mobilization efforts in which there is no blameworthy opponent, no politically relevant distinction between "us" and "them"?* Because social movement insights about collective identity have largely been premised on research about conflict movements involving social groups who confront systems of domination and subordination, theorists have assumed that the importance of group identity for political action lies in its specification of a *blameworthy target*: "we" understand "them" as benefiting from or being responsible for a collectively defined injustice (Gamson 1992a; Klandermans and Weerd 2000; Taylor and Whittier 1992). But in the context of many social rights claims, it is difficult to ascertain who is to blame for the social conditions that give rise to particular needs or problems. In the case of long-term care, for example, there are no obvious

parties to hold accountable for causing chronic illnesses and the disabilities of the elderly, or for trends toward fracturing households that make care responsibilities more difficult, or for the high costs of market-based care. In such contexts, I argue, the importance of collective identity would seem to be less about defining dominant and subordinate relations, than it is about challenging the distribution of public and private resources.

In Chapter 2, then, I examine how collective identification transforms the way in which individuals think about private and public responsibilities of care provision. I find that group identification has important effects on the oppositional consciousness of study participants, but not in the way that traditional theories of collective identity would predict: rather than politicizing caregivers by establishing an “us” versus “them” binary in which group-identified caregivers see their own interests as being harmed by particular blameworthy opponents, collective identity politicized caregivers by redefining caregiver needs as legitimate matters of public concern and establishing caregivers as deserving beneficiaries of public remediation. Because caregiving is generally considered a “natural” extension of family roles, care providers are generally reluctant to identify with a caregiver identity that embraces a more public-oriented understanding of care. As a result, social services and caregiver advocacy organizations have relied on discursive strategies that deliberately *bridge* cultural norms about family responsibility for care provision with an understanding of long-term care as a community or social responsibility (cf., MacDonald and Merrill 2002). This transformation is arguably key to the creation of public demand for public policies involving long-term care: to the extent that long-term care is understood exclusively as the “natural” or “normal” responsibility of families, the costs of long-term care provision are understood as belonging in the domestic sphere. But to the

extent that long-term care is understood as a legitimate political concern, problems of care provision move into the public sphere for deliberation about the distribution of public resources.

A second dimension of oppositional consciousness—also viewed as a necessary condition for collective action—is an injustice framing, an interpretation of previously acceptable or tolerable social conditions as *unfair* or *injurious* (Gamson 1992b; Turner and Killian 1987). In the United States, the discourse of rights has long been understood to be a powerful tool for injustice framing, evoking images of durability and a permanent commitment by the state, while simultaneously retaining a capacity to be repossessed and reimagined by people with widely varying interests (Hartog 1987). Yet while rights discourse in the United States has been useful as a source of injustice frames for a broad range of issues involving individual freedom and political and social participation, its utility in framing injustices involving health and economic security has proven far more tenuous. The failure of a social rights discourse to widely resonate with Americans as a way of constructing grievances raises important questions about how political demand for *new* social rights is created. In Chapter 3, then, I ask: *how do individuals develop oppositional interpretations of longstanding “private” social practices, without recourse to a resonant social rights discourse in which long-term care is envisioned as a public responsibility?*

Drawing on social movement and sociolegal conceptualizations of grievance construction, I trace the circumstances in which caregivers derive alternative interpretations about responsibility for long-term care provision. I find that virtually all caregivers in this study maintained strong commitments to the idea that families should bear the primary responsibility for long-term care on their own; few had any specific ideas when they began caregiving about what the government could or ought to do to assist in long-term care provision. The most

significant source of oppositional interpretations about care provision was California's Medicaid program: long-term care benefits granted only to the poorest members of their community provided caregivers with a concrete example of what they could reasonably expect from the state with regard to assistance, and these expectations in turn formed the basis of their claims for state assistance.

While grievants in this case demonstrated a dramatically expanded understanding of the state's responsibility for helping care providers, that understanding was itself shaped by the fact that the primary *source* of oppositional interpretations of care was a means-tested public assistance program. The underlying logic of a means-tested or needs-based conception of social rights is that *individuals* should take primary responsibility for their own health or economic security, and the government should step in only when individuals cannot satisfy their basic needs. By contrast, the underlying logic of a social insurance conception of rights is that the *state* should provide positive legal entitlements to all eligible citizens in order to lessen the risks of old age, sickness, and disability. When caregivers spoke about state intervention in this case they primarily did so within a means-testing framework, emphasizing not community responsibility or the social responsibilities of care, but the *satisfaction of needs*. I argue that a *needs*-based conceptualization of state intervention resonated with caregivers because it *integrated* new expectations for state assistance with beliefs in the primacy of family responsibility for care. Caregivers, in other words, believed families should be primarily responsible for care provision, but expected the government to provide "help" or "assistance" when families needed it. By contrast, a social insurance conceptualization of state intervention was less resonant among these caregivers because it symbolically suggested to caregivers that the state would be "taking over" long-term care obligations that more properly belonged to the family.

In both processes of collective identification and grievance construction, then, oppositional understandings of care provision depended on a discourse that *bridged* hegemonic understandings of care as a family responsibility with understandings of care as partly a state responsibility. This theme is revisited again in an analysis of the ideological justifications caregivers articulated for state intervention. In Chapter 4, I consider the ways in which caregivers with developing oppositional consciousness connected their experiences to an ideology of the welfare state. *Ideology* is here understood as a well-worked out set of beliefs that links one's understanding of how the world works with values and normative principles relevant to promoting or resisting social change (Oliver and Johnston 2000). I ask: *how do family caregivers making claims for state intervention link their understanding of care dilemmas with normative principles about the state's role in protecting the economic and health security of its citizens?*

The American welfare state, with its "two tiers" of social provision, embodies at least two distinct ideological perspectives on the purposes of social welfare policy (Fraser 1989b): means-tested programs reflect the view that the state should have a minimal role in social provision, granting only temporary, subsistence-level relief to those unable to provide for their own needs, while social insurance programs reflect the view that the primary role of the welfare state should be that of providing citizens with economic security to offset the predictable risks of modern industrial society (Marmor, Mashaw and Harvey 1990). In this chapter, I argue that caregivers' justifications for state intervention in long-term care provision corresponded with neither traditional vision of the welfare state, but instead *blurred* ideological distinctions between "safety nets" and "entitlements," recognizing an expanded role for state assistance for the middle class, but falling short of endorsing principles of social citizenship.

Market-based supportive services such as adult day care, home health care or nursing home care are simply unaffordable for many working- and middle-class caregivers, and the only source of public benefits for long-term care in the United States is Medicaid, a means-tested health program with strict eligibility requirements that screen out all but the very poor. As a consequence, many nonpoor caregivers in this study actively arranged their financial affairs so that their care receiver might qualify for Medicaid—either by shifting assets to other family members with the help of an attorney, or more commonly, by “spending down” the assets of their care receiver until he or she is effectively impoverished. Caregivers justified their pursuit of Medicaid “welfare” benefits by importing the rhetoric of “deservingness”—typically used to distinguish social insurance from “welfare” beneficiaries—*into the context of the means-tested program*, emphasizing their status as workers, taxpayers, and citizens to differentiate themselves from the “undeserving” Medicaid poor. But if in doing so caregivers seemed to *re-cast* Medicaid “handouts” as governmental “obligations” for the middle class, their invocation of deservingness did *not* in most cases signal broad, ideological support for an activist state government. Indeed caregivers routinely expressed skepticism of state authority and government efficiency.

By straddling both ideological visions of welfare state provision, I suggest that caregivers were attempting to reconcile their normative commitments to family care with the contemporary realities of care provision. On the one hand they believed that families should take primary responsibility for care provision and that the government should step in only when they cannot meet their basic care needs. But on the other hand, they held *an expansive definition of “need,”* one that envisions not just the poor, but the middle class, as appropriate—and deserving—beneficiaries of public provision. This evolving understanding of “need”—requiring, in effect, a much broader, more generous, and more inclusive “safety net” for the middle-class—

corresponds with neither tier of the traditional two-tier welfare state framework, nor does it fit neatly into the competing political logics of social protectionist and residualist approaches to social welfare provision. The implications of this political logic for policy reform efforts are considered in Chapter 5.

Each of the first three dimensions of oppositional consciousness—collective identification, injustice framing, and ideological justifications for state intervention—allows us to identify those conditions and experiences that give rise to oppositional interpretations of care provision—a necessary precondition for the construction of “political demand” for new social entitlements for care provision. While many participants in this study demonstrated a fairly well-developed sense of oppositional consciousness, very few had ever communicated their need—or support—for expanded state assistance to elected representatives or participated in any organized, collective effort to obtain policy reforms. In Chapter 5, I consider the possibility that the absence of observed political demand for state assistance for long-term care provision may be due in part to perceptions of *political efficacy*. To paraphrase William Gamson (1995, p. 89), some caregivers may be completely convinced of the desirability of expanded state entitlements, while gravely doubting the possibility of obtaining them. Chapter 5 asks: *In what ways do political opportunities inhibit or encourage caregivers with oppositional interpretations of care provision from participating in efforts to attain policy reform?*

To feel like they can “make a difference,” caregivers require information about when and how they can participate. They need collective action frames and organizational bases for expressing their grievances and acting in pursuit of their interests. For collective action frames to motivate caregivers to participate, they must set forth goals and strategies for achieving policy reforms that are consistent with the needs and experiences of families providing long-term care.

But while a wide range of advocacy organizations exist—some of them, like the AARP, among the largest and most influential in the United States—caregivers in this study were largely unaware of, or disillusioned by organizations pursuing long-term care reform. I argue in this chapter that caregivers’ low participation rates reflect not merely an unwillingness or inability to participate in collective action, as is commonly assumed, but a lack of organizational resources.

My analysis in this chapter departs from traditional studies of efficacy, which have largely emphasized *activists’* perceptions of political efficacy, rather than those individuals who are presumably the targets of mobilization efforts. By privileging the views of organizational actors—effectively using the views of activists as a proxy for the views of potential participants—traditional studies of efficacy have tended to miss the ways in which the interests of each group may differ—and at times conflict. In this chapter, I distinguish between *organizational efficacy*, or the perception among activists that movement organizations can alter conditions or policies through collective action, and *individual efficacy*, or the perception among caregivers that their own contribution in collective action can make a political difference. Comparing how activists and caregivers “read” opportunities for political action, I find that not only do perceptions of organizational and individual efficacy differ, but it is this divergence that explains why so few caregivers communicate their claims for state intervention to policymakers.

I argue that the relatively “new” social needs of families struggling with contemporary care dilemmas pose a particular challenge for reform organizations, as their capacity to mobilize caregivers and influence policymakers is substantially limited by the political structures of the “old” welfare state (cf., Esping-Anderson 1999). Existing systems of social provision—as well as the discursive politics that accompany them—sharply constrain the ability of advocacy organizations to identify caregiver constituents and obtain programmatic solutions that would

ameliorate the strains of contemporary care provision. These constraints on organizations in turn affect the perception among individual caregivers that they have the political efficacy to change the terms and conditions of their everyday lives.

Here, then, we arrive at the very place we started: contemporary debates about social welfare issues are shaped by struggles to preserve or restructure existing systems of social welfare provision. But the new social risks associated with care provision today—as well as the emergent political demands for state intervention that such risks may create—do not fit neatly into any existing social welfare structures, nor do they clearly align with the dominant ideological positions on the role of the welfare state. Caregivers invoke the state’s protection to the extent that they demand solutions that protect the middle class from falling into destitution over circumstances beyond their control, but they are wary of solutions that detract—even symbolically—from the family’s primary role as care providers, preferring instead to think about government “as there when we need it.” In the end, it would seem that the novelty of the emerging consensus among caregivers about the state’s role in care provision may be both its greatest weakness and its strength. Because caregivers’ claims for state intervention evade easy classification within the terms of contemporary political discourse, it is difficult for organizational advocates to pursue programmatic solutions that both resonate with constituents *and* with dominant political discourse. And yet, as policymakers seek to modernize social welfare programs in the current context of “permanent austerity,” it may be that caregivers’ vision for state intervention, blurring distinctions between these competing ideologies, points the way to a future political compromise for new long-term care entitlements for American families.

### III. RESEARCH DESIGN AND METHODOLOGY

The emphasis on political consciousness in this dissertation represents a significant departure from most studies of the politics of social provision. Empirical research in this literature has largely focused on macro-level politics—the ways in which the political economy, institutional structures, party alignments, and interest groups shape policy making (e.g., Esping-Anderson 1990; Huber, Ragin and Stephens 1993; Pierson 2001b; Steinmo and Watts 1995), and conversely, the ways in which policy structures shape subsequent welfare state politics (e.g., Hacker 2002; Pierson 1993; Pierson 1994; Skocpol 1992; Soss and Schram 2007). Micro-level, or “bottom-up” analyses in the welfare state literature have been limited to attitudinal research (but see Soss 2002) about specific social problems, public policies, and program beneficiaries (Cook and Barrett 1992; Jacobs 1993), or to research about political participation (Campbell 2003; Verba, Schlozman and Brady 1995). Social movement and sociolegal researchers, by contrast have often taken a more constructivist approach to studying the views of everyday people. Rather than analyzing attitudes and beliefs as fixed attributes, the study of political consciousness analyzes the *development* of attitudes and beliefs, emphasizing the contexts in which individuals form and use such understandings to guide their actions (Ewick and Silbey 1998; Mansbridge and Morris 2001; Morris 1992). Thus, where opinion research emphasizes what people think about a given social problem, research on political or legal consciousness focuses on those conditions and experiences that give rise to the belief that there is a social problem at all.

This constructivist approach has been particularly widely used among sociolegal scholars seeking to understand the development of *legal consciousness*, or how ordinary Americans understand, interpret, and use the law (Ewick and Silbey 1998; Merry 1990; Nielsen 2000).

These micro-level analyses of meaningmaking have been criticized, however, for disproportionately emphasizing the role that legal norms and institutions play in helping citizens resolve *personal conflicts*—with family, neighbors, coworkers, employers, or strangers on the street—rather than how individuals connect their personal experiences with broader collective challenges to the state or social institutions (see Levine 1990; Silbey 1990). By contrast, the focus of this study is on precisely that question: how do individuals’ personal experiences with care provision transform their understanding of their relationship to the state and the state’s obligation to offset social risks by providing economic entitlements? In this vein, I also seek to extend the scope of legal consciousness research, which has tended to emphasize individual “civil” or “political” rights (Marshall 1992 [1950])<sup>11</sup> by focusing on the construction of “social” rights claims to economic or health security.

Finally, the research design in this dissertation also departs from traditional social movement analyses. While social movement researchers have long been interested in questions about the construction of social protest, the focus of their analyses has largely been on *social movement elites*—the messages that movement organizations and leaders deploy to mobilize constituents and acquire new resources, as well as how they negotiate the competing messages of other movement organizations, opponents, and the mass media (Gamson and Modigliani 1989; Klandermans 1988; Snow et al. 1986). Few social movement researchers have studied the processes involved in the construction of political consciousness among individuals who are *not* involved or affiliated with a reform movement or its organizations (but see Hull 2001). William Gamson, more than any other, has made this question central to his work. In *Talking Politics*

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<sup>11</sup> While these studies overwhelmingly focus on employment rights (Albiston 2005; Engel and Munger 2003; Marshall 2003; McCann 1994; Quinn 2000), they have also examined rights to free speech (Nielsen 2004) and privacy (Gilliom 2001), and the right to marry (Hull 2006).

(1992b), Gamson analyzed the construction of political consciousness in conversations with small groups of working-class Americans. Using the conversation in each “peer group”<sup>12</sup> as the unit of analysis, Gamson analyzed how participants constructed opinions about four controversial issues posed by the researcher and what their discourse revealed about the political consciousness of the participants. Gamson’s design provides a useful model for researching groups who have not successfully organized as a political constituency, but the artificiality of the group conversation—four unrelated issues selected by the researcher—tells us little about how political consciousness is shaped *within the context of citizens’ everyday experiences*. Studying the development of political consciousness in everyday life is made more difficult by the fact that it is a subjective process, requiring techniques for observing how individuals evaluate their experiences or conditions while minimizing reactivity to researcher suggestion (see Felstiner, Abel and Sarat 1980-81).

To address these methodological concerns, this study employed a three-stage observational design: nonparticipant observation of support group meetings for family caregivers, peer group discussions involving the same support groups, and one-on-one interviews with group participants. Over a four-month period in the fall of 2004, I observed 68 meetings (1-2 hours in length) of 14 different support groups for family caregivers in Los Angeles. The City of Los Angeles offered the benefits of a large and strikingly diverse population, as well as a developed social service sector supporting a network of support groups for caregivers dealing with a wide range of diseases and disabilities. I compiled a list of support groups from state,

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<sup>12</sup> Traditional focus groups are typically composed of seven to ten participants who are unfamiliar with each other and who will likely never see each other again. The interaction often resembles a group interview more than a discussion, with the researcher playing an active role. In his study of the construction of political consciousness, Gamson relied on an alternative, “peer group” design that involved small groups of familiar acquaintances rather than strangers, and played down the facilitator’s role in keeping the conversation going.

county, and city social service websites, the Alzheimer's Association, and the Los Angeles Caregiver Resource Center. Because race, ethnic, and class stratification in Los Angeles occurs largely along geographic lines, I selected support groups located in most of the key "neighborhoods" of the greater metropolitan area.<sup>13</sup> This ensured a relatively diverse sample with respect to a variety of socio-economic indicators. (Descriptive statistics for the sample can be found in Appendix A).

To control for variability in caregiving experiences across diseases or disabilities, support groups were limited to two specific classes of diseases: dementia and cancer. The burden of caregiving is well known to be greatest among those caring for patients with dementia (cf., Dunham and Dietz 2003), and it is these 10 caregiving support groups that were the primary focus of the study. The burden of caring for family members with dementia is exacerbated by the fact that the costs of supportive services for patients with dementia are rarely covered by Medicare or private health insurance policies. Because the costs of caring for patients with cancer are more frequently covered by health insurance plans, the smaller group of cancer caregivers provided a useful comparative group for examining the extent to which coverage for supportive services influenced the development of oppositional consciousness.

For each support group, I initially contacted the group facilitator to explain the purpose of the study and seek permission to observe the group. In some cases, the facilitator sought permission from group members before I attended any sessions. In other cases, I was asked to attend a meeting to explain the project in person. In all cases, group members were assured confidentiality. If any member was uncomfortable with my presence, they were told to speak

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<sup>13</sup> These included: Santa Monica, West Los Angeles, Fairfax/West Hollywood, North Hollywood, downtown Los Angeles, East Los Angeles, the San Fernando Valley, Pasadena, and some surrounding suburbs.

either directly to the facilitator or myself, and I would immediately leave. None of the participants in the study ever exercised this option. At each meeting, I explained the project to any new participants and sought permission from them to observe the session. In total, 158 caregivers participated in the first phase of the study.

In the second phase of the study, I led nine support groups in a peer group discussion about specific legislative initiatives involving long-term care. Eighty (80) support group members participated in this phase of the study.<sup>14</sup> The purpose of the peer group meetings was to observe how participants related their personal caregiving experiences to larger socio-political issues of long-term care provision, and how they envisioned “solutions” to the dilemmas raised in providing long-term care. During the peer group sessions I introduced four general policy proposals (pertaining to funding for respite care, caregiver allowances, tax credits for caregiving expenses, and paid family leave) and asked participants to discuss how the proposals would affect their personal situations and to consider the benefits and drawbacks of each proposal. At the end of the discussion, participants were asked to raise any areas of care provision that had not been addressed by the proposed policies.

Finally, I conducted one-on-one in-depth interviews with 66 support group participants to elicit more intensive discussions about their caregiving experiences, including their utilization (or nonutilization) of supportive services and benefits, their political backgrounds, and their views of state, market, and family responsibility for long-term care.<sup>15</sup> All support group members were invited to participate in an interview. The semi-structured interviews, which

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<sup>14</sup> All support group members were invited to participate in the focus groups. Focus group participants received \$50 for their time. Funding for the focus group stipends was provided by a National Science Foundation Dissertation Improvement Grant.

<sup>15</sup> To identify any possible sequencing effects in this design, I reversed the order of the interviews and peer group session for one support group. No significant effects were observed.

ranged in length from thirty minutes to two hours, allowed participants to emphasize those aspects of their experiences that they perceived to be most important to them and to describe them in their own words. For the 50 respondents who had participated in the first and second phases of the study, the interviews also provided an opportunity to explore the assumptions and reasoning behind comments made at other points during the observation period.

This multi-method approach was designed to compensate for the limitations of each individual method with respect to the issues of researcher reactivity and control. Nonparticipant observation provided a window into processes of grievance and meaning construction with minimal researcher reactivity. I played a passive role in observing the conversation of meetings, neither asking questions nor controlling the subject matter of the discussion. But to the extent that nonparticipant observation minimized the effects of reactivity, it also minimized my control over the substance of participant conversations. One-on-one interviews provided a way to elicit more specific and focused information from respondents. Yet even the most carefully-crafted questions run the risk of influencing respondent perceptions and responses. Peer groups are something of a middle-ground, permitting observation of the interaction of participants and the interplay and modification of ideas (Albrecht, Johnson and Walther 1993), while also serving as a useful tool for observing the natural vocabulary with which participants construct meaning about specific issues posed to them.

One could reasonably argue that in recruiting participants from support groups, the project runs the risk of sampling on the dependent variable, as family caregivers who join support groups—a semi-public forum—are likely to be relatively more politicized than caregivers who have not joined support groups. To assess the effects of selecting participants based on support group participation, I also interviewed a smaller sample of 13 unpaid family

caregivers who had *not* joined support groups. These caregivers were recruited by support group facilitators (who were often social workers with a client base outside of the support group) and the Los Angeles Caregiver Resource Center to ensure that participants had approximately the same level of contact with supportive services as support group participants.

In a similar vein, a number of limitations on the representativeness of the sample should be noted. Not only did I recruit caregivers who had already made contact with social services (an important step, as this study demonstrates, toward politicization), but they were living in Los Angeles (a notoriously liberal metropolitan area in a famously Democratic state) and they were primarily caring for patients with dementia (one of the most challenging and expensive health conditions for family caregivers). In this regard, I would expect the prevalence of oppositional interpretations of care provision to be lower among caregivers who have not made contact with social services, who are living in rural and/or socially conservative parts of the country, and who are caring for patients with shorter-term, or less costly forms of chronic disease. However, I should emphasize that the sample for this study was not intended to be representative of all “family caregivers.” Nor was the purpose of the study to calculate *how many* caregivers hold oppositional interpretations of care provision. Rather, the study was designed to identify those conditions and experiences that give rise to oppositional interpretations of care provision and to evaluate how norms about family responsibility for care shape claims for state intervention.

Finally, to identify the role of organizational actors in shaping the political consciousness of family caregivers and to get a sense of the broader social and political context in which family caregivers sought solutions to their care dilemmas, I conducted in-depth interviews (typically 30-45 minutes in length) with social workers and caregiver advocates at the local, state, and national levels. I interviewed twelve of the support group facilitators in this study, most of whom were

licensed social workers,<sup>16</sup> to solicit their views on the dynamics of their support groups, the availability of social services for caregivers in Los Angeles, the recurring problems their clients face as caregivers, and the conditions that change caregivers' views about the relative responsibilities of family, market, and state for care provision.

I also conducted interviews with 29 staff and leaders from 20 local, state, and national advocacy organizations pursuing long-term care policy reform. Because there is no comprehensive long-term care public policy at either the federal level or in the state of California, the administration and delivery of services and benefits for patients with chronic diseases or disabilities takes place within a patchwork “system” of administrative agencies, nonprofit organizations, and for-profit care facilities. To solicit impressions of reform opportunities from advocates who interact with these different dimensions of long-term care provision, I defined “advocacy organization” broadly to include any organization seeking to influence public policy and resource allocation decisions within political, economic, and social institutions (cf., McConnell 2004). This definition includes not only organizations that seek to influence local, state or federal elected officials through *legislative advocacy*, but also organizations that specialize in *administrative advocacy*, or efforts directed at government agencies such as the Center for Medicare and Medicaid Services or the California Department of Social Services; *program advocacy*, or efforts directed at changing organizational practices within service organizations (such as nursing homes), or at improving the quality of and access to supportive services; and *legal advocacy*, or efforts to enforce and expand the rights of caregivers through the courts. Appendix B lists each participating organization and the primary form of advocacy in which they specialized.

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<sup>16</sup> One facilitator was a licensed clinical psychologist, and two others held degrees in family therapy.

Interviews with respondents from these organizations sought information on the primary mission, goals, and strategies of their organizations, their perceptions of caregivers as a constituency (including characteristics of caregivers that make them more or less likely to mobilize for collective action), their relationships with other organizations that pursue long-term care reform, and their perceptions of the contemporary politics of long-term care policy reform, including the primary obstacles to reform efforts at the state and national levels.

Fieldnotes from observations, taped focus group conversations and interviews were transcribed and analyzed using *Atlas.ti*, a qualitative analysis software program that allows researchers to identify and code themes from transcripts. I elaborate the specific coding schemes used to analyze each of the four dimensions of political consciousness in the chapters that follow.

#### *IV. SUMMARY OF CONTRIBUTION*

The objective of this dissertation is to examine the significance of political consciousness in mediating between emerging social needs and political demand for new social entitlements. Using the case of long-term care in the United States, I seek to understand how individuals navigate between traditional beliefs about, and new realities of family life, and how their experiences shape their understanding of the interface between family, market, and state responsibility for the costs and provision of care. Drawing on the concept of oppositional consciousness to identify the conditions under which family caregivers challenge norms about the private responsibility for family care and reconceptualize care provision as a community or social responsibility, I consider four sets of questions: *First*, what role does collective identity play in contexts in which the “opposition” is not a blameworthy opponent, but an ideology involving longstanding norms about the distribution of public and private resources? How and when do family care providers come to identify with a “caregiver” group identity, and what

effects does group identification have on caregiver understandings of private versus public responsibility for long-term care provision? *Second*, how do individuals develop an injustice frame about private, family care provision without recourse to a resonant social rights discourse in which long-term care is envisioned as a public responsibility? *Third*, to the extent that family caregivers articulate claims for state intervention in long-term care, how do they link their understandings of care dilemmas with an ideology, or a set of normative principles about the state's role in social welfare provision? How, in other words, do family caregivers understand the role of the state in protecting citizens from the contemporary risks associated with long-term care provision? *Fourth*, in what ways do political opportunities inhibit or encourage caregivers with oppositional interpretations of care provision from participating in efforts to attain policy reform? To what extent can we attribute the low level of demonstrated political demand for state assistance among family caregivers to perceptions of *political inefficacy*?

Together, these four dimensions of oppositional consciousness paint a portrait of American families with deeply-held beliefs about family responsibilities for care *and* significant care needs that cannot be met through private sector solutions alone. In these circumstances, oppositional understandings of care provision depend on a political logic that *bridges* hegemonic understandings of family care provision with new expectations for state intervention. Such a political logic is both derived from and constrained by experiences with *existing* social services and public policies. But at the same time, it is a logic borne of new social conditions and shifting norms and beliefs about the appropriate role of the state in social welfare provision. In this respect, the oppositional consciousness of family caregivers may reflect an emerging consensus about how the American welfare state should adapt existing social policies to address the contemporary problems of care provision.

## CHAPTER 2

### THE DILEMMAS OF COLLECTIVE IDENTITY CONSTRUCTION WITHOUT OPPONENTS

*We don't have any real obvious enemies in this process. ... I don't think it's lack of ideas. I think there isn't the political will yet. And there isn't enough political pressure to get it taken care of.*

—Stephen McConnell, Senior VP for Public Policy and Advocacy, Alzheimer's Association

In most contemporary theories for collective action (see, e.g., Fantasia 1988; Gamson 1992a; Klandermans 1992; McAdam 1982; Melucci 1989; Snow and McAdam 2000), collective identity is seen as a necessary prerequisite for (and product of) collective action, providing individuals with a sense of who they are and what they stand for in relation to some group of others (Snow 2001). Seeking to explain precisely how collective identity orients people toward collective action, social movement theorists have commonly assumed that the politicization of collective identity depends on the specification of a *blameworthy target* (Gamson 1992a; Klandermans and Weerd 2000; Taylor and Whittier 1992). Collective identification in this view is seen as an analytically significant step in the formation of oppositional consciousness because it both positions groups in an adversarial relationship *and* specifies causal attribution: “we” understand “them” as benefiting from or being responsible for a collectively-defined injustice.

Because our theoretical insights on the relationship between collective identity and politicization have largely been premised on research about traditional conflict movements involving relationships of inequality or subordination, we know very little about what role collective identity plays in social reform efforts that enjoy broad attitudinal support and encounter little or no organized opposition—what social movement researchers refer to as “consensus movements” (McCarthy and Wolfson 1992; Schwartz and Paul 1992). In the case of

long-term care, there are few obvious targets to blame for the problems faced by contemporary American families. That existing systems of social provision and norms about family caregiving no longer accord with the realities of American family life is due not to the actions (or inaction) of particular institutions or parties, but to a confluence of broad changes in the demographic make-up of the population, health care provision, household structure, and the gender order. It is difficult, for example, to hold anyone accountable for the increasing ranks of the oldest-old, those 85 and older that require intensive levels of personal care, or for the geographic dispersion of American families that makes care provision more difficult, or for the high costs of market-based care. The case of long-term care in the United States, then, presents an opportunity to evaluate what role collective identity plays in politicizing individuals in the absence of a specific, blameworthy opponent.

In this chapter, I argue that collective identity plays a key role in the development of oppositional consciousness of family caregivers, but not in the ways theorists have identified with respect to conflict movements. The relationship between collective identity and politicization rests not in identifying relationships of inequality or subordination, but in (1) reconceptualizing “private” long-term care problems as matters appropriate for state intervention and (2) defining caregivers as deserving beneficiaries of public resources. My analysis of collective identity construction and politicization proceeds in four parts: First, I examine the social construction of the “family caregiver” identity, focusing on the role of social service providers and caregiver advocates in constructing family caregiving as an essential component of our modern health and long-term care system that both needs and deserves public support. Second, I analyze how and when family care providers come to identify with the “caregiver” group identity. Here I explore how social workers, caregiver advocates, and group-identified

caregivers use the discourse of caregiving to bridge hegemonic beliefs in family responsibility with a more public understanding of care provision. By characterizing long-term care provision as work that is above and beyond the “normal” obligations of a spouse or adult child, caregiving discourse validates and makes visible work that is often discounted as “just something one does” for family; yet at the same time, it demarcates a clear distinction between one’s *familial* role and one’s role as a *care provider*, re-framing carework as something that can be shared or purchased rather than contained exclusively within the family. Third, I examine how group identification leads to a politicized understanding of long-term care provision. Noting the ways in which professional and legal/organizational norms in social services proscribe social workers from engaging in overt “political” attempts to link caregiver problems to structural or socio-cultural causes, I find that support groups nevertheless play a distinct consciousness-raising function, emphasizing similarities in the experiences of care providers, reframing their individual care dilemmas as problems shared by caregivers as a group, and highlighting the underlying structural or cultural factors that make long-term care provision difficult for so many families. Finally, I explore the effects of collective identification on the oppositional consciousness of family care providers, comparing how non-identified and group-identified caregivers conceptualize their care problems—as domestic or public policy issues—and how they construct themselves as potential beneficiaries of government assistance. I conclude with some thoughts on the relevance of these findings for theoretical debates about the relationship between collective identity and politicization, and political debates about long-term care provision.

I. *CONTEMPORARY THEORIES ON THE POLITICIZATION OF COLLECTIVE IDENTITY*

Verta Taylor and Nancy Whittier (1992) conceptualize collective identity as “the shared definition of a group that derives from members’ common interests, experiences, and solidarity” (see also Polletta and Jasper 2001). At a more basic level, collective identity refers to a shared sense of “we-ness” (Hunt and Benford 2004), established by not only emphasizing the commonalities among members of a group, but also by highlighting the social, psychological, and/or physical differences between members of a group and “others” in the social world (Taylor and Whittier 1992). But as some have observed (Klandermans and Weerd 2000), in-group/out-group dynamics are easily constructed over any number of characteristics—hair color, music preferences, neighborhoods, professions, hobbies, etc. In order to become an important element of collective action, a group identity must be *politicized*—taken-for-granted assumptions about the needs and interests of a given group must be called into question and become politically relevant to group members as a basis for collective action (Klandermans and Weerd 2000; Taylor and Whittier 1992). Social movement theorists have proposed a number of theories about the mechanisms by which collective identity politicizes individuals. While these theories vary in their focus, they share an emphasis on *adversarialism* and *causal attribution*.

One conceptualization of the relationship between collective identity and politicization connects group identification with *consciousness-raising*. “Boundaries,” Taylor and Whittier (1992, p. 114) observe, “locate persons as members of a group, but it is group consciousness that imparts a larger significance to a collectivity.” In order for people to pursue collective rather than individual solutions to problems, they must agree to a common understanding of their experiences, one that attributes their discontent to structural, cultural, or systemic causes rather than to personal failings or individualized circumstances (Gamson 1992a; Taylor and Van

Willigen 1996). *Consciousness* in this sense concerns the question of how the meaning that individuals give a social situation becomes a shared definition implying collective action (Gamson 1992a).

Because individuals could have potentially unlimited interpretations of the social world, social movements play an active role in providing interpretative frameworks that orient individuals toward specific understandings of their circumstances. Collective action frames emphasize a commonly-shared injustice, attribute the responsibility for the injustice to others, and propose collective solutions (Snow et al. 1986). The feminist consciousness-raising groups of the 1970s are perhaps the best known example of a movement strategy for bridging individual, “personal” grievances to structural, “political” explanations for women’s experiences (Evans 1979; Ferree and Hess 2000). The consciousness-raising process was a four-step discussion in which women first spoke about their personal experiences and then brought their individual experiences into a larger discussion, linking them to societal forces rather than to personal factors. Finally, members of these groups attempted to relate their analyses to other theories of oppression. Verta Taylor and Marieke Van Willigan (1996) have observed similar processes in the self-help groups of the postpartum support and breast cancer movements. In both movements, participants used “survivor narratives,” or public testimony, to transform their private experiences into public events and to normalize experiences widely regarded as deviant. Borrowing from the women’s health movement of the 1970s, movement actors deliberately placed women’s experiences in a larger feminist framework that identified their illnesses as an injustice linked to gender inequality (see also Taylor 1996). In each of these cases, the process of consciousness-raising is understood as more than discovering that one’s individual grievances are shared by a larger group (or, making the personal *public*); the key is developing explanations

for collective grievances that attribute blame to specific groups or institutions whose interests are in opposition to one's own (or, making the personal *political*).

This understanding of the relationship between collective identity and politicization is closely related to a second theory in the social movement literature, one which emphasizes the link between group identification and *grievance construction*. “Without group identification,” Klandermans (2000, p.73 ) observes, “there can be no group deprivation ....” In this view, routine in-group/out-group dynamics become politicized when individuals perceive their relationship to another group to be not only different, but *unequal*—and understand one's own group to be on the losing side of the inequality (Klandermans and Weerd 2000; Mansbridge 2001). The move from “us and them” to “us against them” is thus understood as key to the formation of oppositional consciousness because it both positions the groups in an adversarial relationship *and* specifies causal attribution (Gamson 1992a). “It is this reciprocity of causal attributions and encounters with opponents,” Klandermans (2000, p. 71) concludes, “that produces the potentially explosive mix of shared moral indignation and oppositional consciousness that makes collective identity politically significant.”

This relationship between collective identification and grievance construction has been observed not only in cases of explicit human domination, but also in challenges to more subtle structures of power. A number of movements, for example, have politicized in-group/out group dynamics by using experiential knowledge to directly challenge dominant or conventional forms of knowledge. Thus, the AIDS movement (Epstein 1996) and movements around post-partum depression and breast cancer (Taylor and Van Willigen 1996) have all drawn on shared personal experiences to challenge scientific knowledge systems. Battered women and survivors of rape or incest have similarly relied on shared experiences to challenge legal and medical understandings

of sexual violence (see generally Taylor 1996). In all of these cases, grievances are forged through the same “us against them” dichotomy found in more traditional conflict movements: survivors use their shared status as “lay experts” to challenge “experts” whose scientific or legal interpretations of social problems fail to accurately incorporate the perspectives of those with lived experience.

Whether their emphasis is on consciousness raising or grievance construction, then, social movement theorists seeking to explain the politicization of collective identity assume that collective identity must be oppositional or adversarial for successful politicization to occur. But we know that not all collective action movements are so explicitly conflict oriented. *Consensus movements* are collective actions that enjoy broad attitudinal support and lack well-defined enemies or opponents (McCarthy and Wolfson 1992; Schwartz and Paul 1992).<sup>17</sup> In such movements, the emphasis is less on identifying precisely who is responsible for *causing* collective grievances than it is about specifying who is responsible for *ameliorating* them (Jasper 1998). The distinction between consensus and conflict movements is of course a matter of degree; both types of movements are fundamentally about objections to existing social conditions and about finding solutions (Lofland 1989). But in the case of consensus movements, where there are no clear enemies or opponents, the politicization of collective identity cannot be reduced as easily to an “us versus them” binary. The role of collective identity in such contexts has received relatively little empirical attention, and yet it is precisely this type of movement

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<sup>17</sup> A commonly-cited example of a consensus movement is the movement against drunk driving. Some researchers have characterized consensus movements as systematically avoiding conflict. Lofland (1989), for example, argues that consensus movements in the 1980s were typically nonpolitical, educational, nonpartisan or humanitarian movements. Others have characterized consensus movements not by their ideologies but by their institutional structure and resources, suggesting that such movements are an outgrowth of the rise of professional social movements and the “bureaucratization of social discontent” (McCarthy and Zald 1977; McCarthy and Wolfson 1992; McCarthy and Zald 1973; Schwartz and Paul 1992). In this chapter, I use the term *consensus movement* more broadly to refer to those movements—regardless of ideology or infrastructure—that enjoy high levels of public support and lack identifiable enemies or opponents.

which provides an opportunity for observing how people become mobilized around issues whose legitimacy as matters of public contestation have not yet been explicitly established—or denied.

This chapter thus seeks to build on traditional conceptions of oppositional consciousness (Mansbridge and Morris 2001) by incorporating those contexts in which the “opposition” is not a specific blameworthy *opponent*, as in the case of conflict movements, but an ideology involving longstanding cultural norms about the distribution of public and private resources.<sup>18</sup> In these circumstances, I argue, the term *oppositional* is still appropriate, as it involves interpretations of social conditions that challenge taken-for-granted assumptions about the needs or interests of a given group and re-frame them as legitimate matters of political contestation. As Nancy Fraser (1989a, p.168) observes, what is *political* in the United States is normally defined against what is *economic* or against what is *domestic* or personal. Economic institutions depoliticize issues, in other words, by economizing them—characterizing the issues as impersonal market imperatives or as “private” ownership prerogatives or as technical matters for managers or planners—as opposed to public matters. Alternatively, domestic institutions depoliticize issues by personalizing or familializing them—characterizing issues as private-domestic or personal-familiar subjects rather than public matters. The process of *politicizing* matters, then, involves formulating and legitimating oppositional characterizations that move formerly “private” issues into the public sphere for deliberation.

While efforts to shift the boundaries between the political, economic, and domestic spheres can—and have—encountered blameworthy opponents in, for example, the women’s movement in the United States, one of the challenges of politicizing the issue of long-term care has been the absence of an identifiable adversary. In the case of long-term care in the United

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<sup>18</sup> This process itself can be both conflictual and adversarial, as social groups are typically competing for a scarce pool of public resources. But it suggests a distinctly different role for collective identity.

States, the primary “opponent” for reformers isn’t a specific institution or actor, but a deeply-ingrained cultural ideology that assigns primary responsibility for care provision to the family. Indeed, because the needs of adults suffering from chronic illnesses and old age have historically been absorbed by American families, and women in particular, the primary challenge for reformers is establishing why long-term care should be considered a political—rather than domestic—issue at all. Susanne Mintz, co-founder and president of the National Family Caregiver Association:

[P]eople say well, yeah, this is what we’re all supposed to do. Why is this public policy? People don’t understand why it’s public policy. The answer is that ...we can’t escape the fact that people over 85 are the fastest-growing segment of our population. Over half of them need help with some [activities of daily living].<sup>19</sup> Over half have Alzheimer’s disease. It is public policy now because we have circumstances ... affecting every aspect of our society that we never had before. I would say yeah, it wasn’t public policy years ago. Because you didn’t have long-term care [then].<sup>20</sup>

In what follows, then, I consider the role of collective identification in shifting the issue of long-term care from the domestic to the political arena. In the next section, I outline the specific coding strategies used to analyze collective identity in this study. In Part III, I describe the primary obstacles to collective identification for family caregivers. I then proceed in Part IV with an analysis of collective identity construction, appropriation, and politicization among the family care providers in this study.

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<sup>19</sup> “Activities of daily living” is a clinical term referring to activities involving personal care, such as eating, toileting, getting in and out of bed and chairs, bathing, dressing, and grooming, and managing continence.

<sup>20</sup> Interview with Suzanne Mintz (November 28, 2005).

## II. METHODOLOGY

Social movement theorists have observed that the social construction of collective identity at a group level and the appropriation of collective identity at the individual level should be treated by researchers as distinct phenomena requiring somewhat different methodologies (Gamson 1992a; Klandermans and Weerd 2000). Here I use the term *collective identity* to refer to *group*-level symbols, rituals, beliefs, and values through which collective identity is expressed. As Gamson observes, “We know a collective identity through the cultural icons and artifacts displayed by those who embrace it. It is manifested in styles of dress, language, and demeanor. Collective identity need not be treated as some mysterious intangible but can be as empirically observable as a T-shirt or haircut” (Gamson 1992a, p. 60). I use the term *group identification* or *collective identification* (Klandermans and Weerd 2000) to refer to *individual-level* use of symbols, participation in rituals, and values and beliefs that reflect an individual’s appropriation of a collective identity—what it means to an individual to belong to a group and how he or she includes the collective identity as part of his or her definition of self (see also Snow and McAdam 2000).

My analysis of the “caregiver” collective identity and the symbols, beliefs, and values it represents, is drawn from 42 in-depth interviews with staff at Los Angeles service providers and local, state, and national advocacy organizations, as well as social workers who facilitate caregiver support groups. These interviews elicited perspectives on the relationship between group identification and caregiver utilization of social services and politicization, as well as the challenges of “marketing” the caregiver identity to family care providers. I also examined organizational materials from social service agencies and caregiver advocacy groups—including websites, fliers and informational booklets, newsletters, reports, and books—to identify how

these groups defined “caregivers,” how they presented the needs and interests of caregivers, and what kinds of strategies they recommended for dealing with the challenges of caregiving.

The analysis of group identification among family care providers draws on data from nonparticipant observation of support group meetings for caregivers, focus group discussions involving the same support groups, and one-on-one interviews with group participants. Because processes of identity construction and identification are generally understood as interactional (Melucci 1989), it was important to find a setting in which family care providers had opportunities to jointly construct and give meaning to the experiences of family caregiving. Previous studies on collective identity construction have found that focus groups (Munday 2006) and support groups (Chesler and Chesney 1995; Taylor 1996; Taylor and Van Willigen 1996) are useful contexts for observing ongoing processes of identity construction, and I draw heavily from these aspects of the study design for this analysis. To assess the effects of support group participation on collective identification, I also draw on interview data from the smaller sample of 13 unpaid family caregivers who had *not* joined support groups.

Together, the data on family caregivers offer three perspectives on the processes of identity construction around long-term caregiving. *Retrospective memories* from family care providers who self-identify as caregivers provide insights as to when individuals began to self-identify, and how they experienced the transition; *interactions in support groups* illuminate processes of group identification and its effects, and *interviews with caregivers who have not joined support groups* offer a comparative perspective on the effects of support group participation on group identification.

For this analysis, I coded all references in fieldnotes and focus group and interview transcripts to “identity,” including references that indicated solidarity with or membership in a

larger group (e.g., “we” “people like us”), and instances of self-identification as caregivers. I also noted exchanges between group members (typically new group members) and/or the facilitators about “who is a caregiver” and what being a caregiver “means.” In addition, I coded references to the structural dynamics underlying individuals’ caregiving dilemmas, noting instances in which caregivers connected their care problems to, for example, social values, the health care system, and government distribution of resources. Together, data from family caregivers, social workers, advocates, and organizational and social service materials on caregiving illuminated the processes by which the caregiver identity is constructed, when and how individuals identify as “caregivers,” and how group identification affected the political consciousness of individual participants.

### *III. OBSTACLES TO COLLECTIVE IDENTIFICATION IN THE CASE OF LONG-TERM CARE*

Family care providers are generally reluctant to view themselves as part of a larger group or constituency. In one of the few surveys conducted with a nationally representative sample on the issue of caregiver self-identification, the AARP found that nearly half (45%) of survey respondents who were providing care for a relative or friend with a disability or chronic disease would not identify themselves as caregivers (Kutner 2001). Previous research has found that identifying oneself as a “caregiver” for an adult family member with a chronic disease or disability is the most significant variable in determining to what extent family care providers take self-help actions, such as arranging for supportive services, reading about caregiving, asking for help with caregiving, talking to a professional about one’s own health, discussing caregiving with a supervisor, or joining a support group or caregiver organization (Kutner 2001; National Family Caregivers Association and Caregivers Advisory Panel 2001). Evidence also suggests

that self-identification leads to increased confidence when talking to healthcare professionals about a family member's care (National Family Caregivers Association and Caregivers Advisory Panel 2001). Given these positive effects of self-identification, why are family care providers so reluctant to view themselves as “caregivers”?

Their reluctance can be attributed to at least two sets of factors. First, the caregiving role often evolves out of a pre-existing *familial* role—husband or wife, daughter or son—and caregiving is generally considered a “natural” extension of these family roles (O'Connor 1999). Like other forms of domestic labor in this country, caregiving is understood as more “naturally” an extension of women's family roles than men's: women not only represent three-quarters of all caregivers in this country (Health & Human Services 1998; Health and Human Services 2003),<sup>21</sup> but they generally spend 50% more time providing care than male caregivers (Health & Human Services 1998).

It is only when the demands of caregiving have transitioned well beyond the responsibilities typically associated with being a partner or adult child, that family care providers will identify as caregivers, if at all (Montgomery and Kosloski 2001). Because care expectations differ for spousal and child roles, this affects how quickly spousal and adult child caregivers self-identify. Spousal caregiving typically emerges out of a reciprocal relationship where two people have made a personal and legal commitment to care for one another. Thus, when a dependency situation emerges in a spousal relationship, it is often difficult for spousal caregivers to discern changes in the nature of the relationship, as caregiving is almost always part of the spousal role (Montgomery and Kosloski 2001). Notably, while gender norms may make it more likely that care responsibilities will fall on women than men, they do *not* necessarily make it easier for men

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<sup>21</sup> Three-quarters of the participants in this study were women as well.

to discern the onset of a “caregiving” role.<sup>22</sup> Male and female spouses are quite similar in their tendency to view caring for a sick or disabled partner as a logical extension of the marital relationship; both males and females understand being a “good” husband or wife to involve taking care of one’s partner “in sickness and in health” (O’Connor 1999).<sup>23</sup> Caregiving frequently involves a re-ordering in the gendered household division of labor—regardless of which spouse is sick. But even when caregiving involves new tasks for a spouse, those tasks are still viewed as part of the *spousal role*. By contrast, caregiving by adult children often involves not just new tasks but a change in the very nature of their relationship to their parents—after a lifetime of being “dependent” on parents for support, assisting a parent typically represents a dramatic role shift for adult children. Because this transition is far more noticeable for adult children, they are more likely to identify as “caregivers”—and to identify earlier in the caregiving process—than spousal caregivers (Montgomery and Kosloski 2001). The imbrication, then, of the family and caregiving roles means that identification as a *caregiver* is often not about identifying with a larger group of similarly-situated people, but about acknowledging a significant, and emotionally difficult transition in the relationship between the caregiver and care receiver.

A second obstacle to group identification is that in many cases identifying as a “caregiver” involves making public what has long been considered a private, family matter. The belief in taking care of one’s own, of “handling” the issue within the family, and the fear and guilt of being viewed as a “bad” son or daughter or deficient spouse for seeking assistance with

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<sup>22</sup> In this study as in other studies (Kutner 2001), women were slightly *more* likely than men to self-identify as caregivers.

<sup>23</sup> Research suggests, however, that male caregivers tend to use paid supportive services such as in-home care more frequently than female caregivers (Winslow 1997).

caring for a loved one, all reinforce an understanding of caregiving as a private and individual, rather than public or social responsibility (Abel 1991; Brody 2004). In addition, the stigma of dependency in American culture (Fraser and Gordon 1994) adds to family pressure to keep the loss of independence and disability associated with chronic illness within the privacy of the home.

Faced with such longstanding and deeply-held beliefs about family responsibility for care provision, reformers seeking to establish a more publicly-oriented understanding of care must find a way to transform how family caregivers think about their relationship to their care receivers and the duties of care. Through collective identification, I argue, caregivers not only reconceptualize what they understand to be the “natural” or “normal” responsibilities of families, but they reframe their personal caregiving dilemmas as public policy issues and their work as caregivers as a vital social contribution.

#### IV. PROCESSES OF COLLECTIVE IDENTIFICATION

##### A. *The Cultural Production of the “Caregiver” Identity*

While California social services have provided state-wide program assistance to family caregivers since 1984,<sup>24</sup> the notion of caregivers as a *group* or *constituency* did not emerge in public discourse until relatively recently. Beginning in the early 1990s, a spate of newly-founded national caregiver advocacy organizations,<sup>25</sup> together with existing social service providers, began a concerted effort to increase public awareness of family caregiving issues in

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<sup>24</sup> In 1984, California enacted the Comprehensive Act for Family Caregivers of Brain-Impaired Adults, which established the statewide California Caregiver Resource Center (CRC) system under the California Department of Mental Health—the first of its kind in the nation.

<sup>25</sup> The National Family Caregivers Association was founded in 1993. The National Alliance for Caregiving was created in 1996. And in 2001, the National Center on Caregiving was formed to advance the development of programs and policies for caregivers in all 50 states of the country.

the United States. As these advocacy organizations and social service providers sought to make visible the challenges of care provision for contemporary American families, they increasingly settled on the vocabulary of *caregiving* to describe the hands-on physical assistance and emotional and financial support historically performed by spouses and children for their family members. The terminology caught on quickly. Until 1997, the term “caregiver” could not be found in any English language dictionary (Goldman 2002, p.3). The occurrence of the term in headlines of U.S. newspapers and magazines in the five-year period from 1996-2001 was more than three times that found in the period from 1990-1995 (Kutner 2001). Today, websites, magazines, and mass-marketed self-help books all rely on the discourse of “caregiving” to talk about issues relating to care provision for family members suffering from chronic illnesses, injuries or consequences of old age. Similarly, local, state and national advocacy organizations as well as social service providers (including city and county service agencies, adult day care centers, senior centers, in-home care services, and legal services organizations) all promote their programs and services in the discourse of caregiving. In Los Angeles, the site of this study, fliers advertising workshops, classes, support groups, and care consultation for family care providers illustrate the emphasis on caregiving terminology:

“Taking Care of You: Powerful Tools for Caregivers”  
(flier advertising 6-week class sponsored by the LA Caregiver Resource Center)

“This Day’s For You – Caregiver Wellness Day”  
(flier advertising 1-day conference sponsored by Alzheimer’s Association)

“For You, The Caregiver, We Offer...Individual counseling, weekly support groups...”  
(Advertisement in newsletter put out by Wise Adult Day Service Center)

“48 Hour Caregiver Retreats”  
(flier advertising 2-day retreat sponsored in part by LA County Area Agency on Aging and the LA Caregiver Resource Center)

“Caregiving: A brief Guide to the healthcare benefits, legal options and support services available to caregivers and their loved ones.”  
(educational brochure published by Bet Tzedek Legal Services)

But even as LA social service providers and caregiver advocates draw on the vocabulary of caregiving to publicize their program services and benefits and advance their public policy goals, they widely acknowledge that the caregiver identity is not one with which most families resonate. Ann Hammond, President of a coalition of Los Angeles County adult day service centers:

A lot of the people are out there giving care to their loved ones who do not identify as caregivers. And so if they see a caregiver support group...they're clueless. ... And that's something the Coalition struggles with, it's something that each [day care] center struggles with. How do we market? We know that there's a body of people out there who need our services. How do we reach them?

Acknowledging the problem of nonidentification among potential beneficiaries, service providers in Los Angeles (including the City's Department of Aging) have hired marketing and public relations firms to devise strategies for reaching family care providers who have *not* identified as caregivers.<sup>26</sup> The LA Caregiver Resource Center and Alzheimer's Association have both produced brochures, for example, that ask whether the reader helps a family member with any of the tasks in a checklist of activities (e.g., Do you do shopping for a family member?). The brochure indicates that if the reader has checked "yes" to two or more of the listed tasks, then he or she is a caregiver. Donna Benton, Director of the LA Caregiver Resource Center:

[W]hy is it important to understand this word? Why do you use the word *caregiver*? Because ... if you don't know the magic word, which is called *caregiver*, you may be missing out on benefits for you as a caregiver. So while we understand that you just consider yourself a spouse or parent or you're just the daughter, you know, doing what you normally do, there's this other word called *caregiver*. So it's ...very much through education and always defining, giving the operational definition.

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<sup>26</sup> In 2001, the National Family Caregivers Association and the National Alliance for Caregiving jointly commissioned a marketing firm to conduct "message testing" of various materials for a nationwide public education program.

Both the LA Caregiver Resource Center and the Alzheimer's Association take pains to distribute their literature in a wide variety of settings: senior centers, churches, health fairs, doctor's offices, hair salons, laundromats, and employer assistance programs and other work settings. The LA Department of Aging arranged with the Department of Water & Power to include a brochure on social services with monthly electric bills for all city residents. Similarly, the Alzheimer's Association routinely purchases air time on talk radio stations in Los Angeles to increase public awareness about the disease and its caregiver support programs.

But as we've seen, resistance to identifying as "caregivers" in many cases has very little to do with definitional confusion about caregiving, but instead is rooted in deeply held cultural understandings of family responsibilities for care. The caregiver identity constructed by social services, caregiver advocates, and popular magazines and books in many ways challenges these traditional understandings of family caregiving by characterizing caregivers as making a public or social contribution. Emphasizing care provision as an essential component of our modern health and long-term care system, with care responsibilities—and costs—far more significant than families in the United States have ever faced before, caregiving discourse portrays families as performing a valuable service that is entitled to public recognition and support. How do family care providers identify with an understanding of care that differs so markedly from longstanding cultural norms about care as exclusively a family problem? In the next section, I analyze the discursive strategies used by social workers and caregiver advocates<sup>27</sup> to bridge the two paradigms for understanding care provision, simultaneously affirming the belief in taking care of one's family but also introducing a more publicly-oriented understanding of care.

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<sup>27</sup> As I elaborate in Chapter 5, caregiver advocacy organizations had very little name recognition among family care providers in this study. For most study participants, their primary contact with caregiving discourse was through social services.

*B. Caregiving Principles and Processes of Group Identification*

The process of group identification in the case of long-term care involves much more than adopting the caregiving jargon used by social services; rather it requires a fundamental transformation in how one thinks about one's relationship to the care receiver and the duties of care. Social workers and caregiver advocates rely on two themes—the principles of self-care and self-advocacy—to provide family caregivers with a way of making a conscious distinction between one's responsibilities as a family member and one's role as caregiver. By characterizing long-term care provision as work that is above and beyond the “normal” obligations of a partner or child—as something that can be shared or purchased—rather than just “what you do” for family, caregiving discourse validates and makes visible the efforts of family care providers, and re-casts caregivers as performing a valuable public service.

Because individuals typically begin caring for a spouse or parent as a natural extension of their familial role, there are strong emotional reasons—love, obligation, grief, fear—for not only assuming care responsibilities, but in many cases prioritizing the needs of the care receiver over their own, even when the burden of care affects their own physical and emotional health. Bethany Williams<sup>28</sup> and Elizabeth Foster, support group co-facilitators and licensed family counselors, noted that clients often describe themselves as losing their sense of self in the caregiving role. “[A]ll of a sudden their entire focus ... is on the person they're taking care of. And they get lost in the midst of it,” Williams observed. Foster agreed: “One of my clients gave me ... a picture of a woman with a paper bag over her head, because she said that's how I feel. Like she had lost herself, because she had become a caregiver. That's really a recurring theme, I find. That they feel like they don't have a life anymore.” Gender norms in the United States—

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<sup>28</sup> The names of support group facilitators are all pseudonyms, to protect the identity of caregiver participants.

which often socialize women to defer to the needs of others and to derive their sense of self through relations with others—make women more susceptible to this loss of self than men, and it is generally more common to see women struggling with the ability to establish clear and identifiable boundaries in caregiving than men (cf., O'Connor 1999). But it is important to emphasize that men also struggle with the demands of meeting their perceived obligations as “good” husbands and sons, and in this study many of the male caregivers struggled with being “on call” around the clock in the same way as their female counterparts.

Because so many caregivers feel guilty or selfish for taking time to do things for themselves, a common strategy for convincing caregivers to consider sharing care responsibilities is to frame self care as being good for the *care receiver* (cf., MacDonald and Merrill 2002). The following excerpt from a chapter on “Taking Care of You” in *The Caregiver Helpbook*, a textbook accompanying a six-week caregiving class offered by the LA Caregiver Resource Center, captures this theme well:

When you board an airplane, the flight attendant gives several safety instructions. One of them is, “If oxygen masks drop down, put on your own oxygen mask first before helping others.” This is because if you don’t take care of yourself first, you may not be able to help those who need your help. It’s the same thing with caregiving. When you take care of yourself, everyone benefits. Ignoring your own needs is not only potentially detrimental to you, but it can also be harmful to the person who depends on you (p.1).

To emphasize the importance of seeking help with care provision, support group facilitators and participants frequently cited statistics about the impact of caregiving stress on the health of family caregivers. Empirical studies have found that caregivers are at risk for a wide variety of physical and mental health problems, including increased blood pressure and insulin levels (Cannuscio et al. 2002), depression (Schulz et al. 1995), and cardiovascular disease (Lee,

Colditz and Berkman 2003). One study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than non-caregivers of the same age (Schulz and Beach 1999). Diane Roselli, a social worker and facilitator of a caregiver support group at an adult day care center, noted that she often points to such studies as a way of persuading caregivers to seek outside help.

I give them...a healthy dose of fear. [laughs] I know that sounds terrible, but it's the reality. It's the reality because they're going to burn out and they're going to come down with debilitating illnesses before their loved ones do. And so I tell them that...[T]he effects of stress are going to take you out before the effects of the dementia are going to take out your loved one. ... It's really hard. There's a lot resistance there.

Social workers observed that support group participation is a particularly effective way of overcoming the resistance to seeking help with caregiving, as the group provides a space for caregivers to reinforce the principle of self-care through experiential knowledge. "I can tell them ...your health is going to go downhill, and this, that and the other," observed Roselli. "But that only holds a little bit of weight. But when they hear other people in similar situations ... just seeing other people walking through the same experiences and people saying you know, 'I was terrified to leave my husband at home, but I did it.' ... Then they see it's within their grasp." The following interaction in a cancer support group between Nancy,<sup>29</sup> a new participant, and the rest of the group illustrates how the principle of self care is often communicated and reinforced by sharing experiential knowledge. Nancy had confided to the group that the stress of caring for her mother had begun to take its toll on her health.

Nancy: I'm Italian and my family comes first, and it just kills me that I can't be there. But yet when I go up there, I want to kill her. And I can't yell at her because she'll say don't yell at me, I've got cancer. And my dad is just overwhelmed.

Miguel: I hear that you are trying to fix them all.

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<sup>29</sup> All names of caregivers used in this paper are pseudonyms.

Nancy: You just want to help!

Miguel: ...You need to take care of yourself first. We collapse otherwise. We think it's selfish and that we're being bad, but it's one of the many things I learned here. If I'm not balanced, I'm going to say fuck it and walk out.

...

Rhoda: You're in the beginning stages. I'm going through it again, just listening! I was exactly like you. I felt all of it—the frustration, the anger, the pain, the crying.

Frank: The helplessness.

Rhoda: It does get better. You learn how to deal with it. ... I quit my job to take care of [my husband]. He had his esophagus removed, which is a very very invasive surgery. He spent five months on a feeding tube. The stress was just unbelievable. You feel like you have to hold up him, me, my kids. You have to take care of yourself.

The principle of self-care—articulated at least once in virtually every support group meeting in this study and *always* emphasized with new participants—was typically accompanied by a related principle of self-advocacy. Social workers and support group participants emphasized that reaching out for help was not only a way to preserve one's emotional and physical wellbeing, but it was a way to increase one's sense of personal efficacy in a context in which one typically has very little control. A brochure entitled "Choosing to Take Charge of Your Life: A Self-Advocacy Message for Family Caregivers," published by the National Family Caregiver Association captures this message well:

Obviously you cannot control everything that happens to you or to your loved one. But even though you don't have that power, you do have the power to make active choices about how you are going to deal with the caregiving circumstances of your life.

Social service agencies reinforced this principle by providing a wide range of classes, workshops, and informational brochures on communicating effectively with health care professionals and insurance companies, tips for hiring home help, financial planning, information on applying for public benefits, and legal advice on power of attorney for health care, durable power of attorney, conservatorships, wills and trusts, and nursing home rights. All of these

resources were designed to equip caregivers with the skills to be advocates for themselves and their family members and to make educated choices about how, and under what conditions, they provide care.

The following support group interaction illustrates how facilitators and group-identified caregivers reinforced the twin principles of self care and self advocacy. When Myra first joined her dementia support group, she was quite visibly at a breaking point, describing herself as frustrated, resentful, and angry. In this exchange, other support group participants take her to task for not making active decisions to improve her care situation:

Carolyn: We make decisions about our lives. You know how to. You have the skills . . . but you're not using those skills to change your situation. You've forgotten how to do for yourself. So how do you get yourself out of that loop?

Myra: That's such a good question.

Carolyn: We have this tendency to keep stirring the same pot of shit. The past is over, it's dead. You need to come up with something to do right now!

Myra: Being in charge suited me fine. I consider myself a strong person. I'm used to making the decisions.

Reba: But you don't know how to take care of yourself.

Facilitator: Did anyone come here knowing that?

(Everyone shakes their head no.)

Facilitator: It's a process.

The implicit message in encouraging new caregivers to get themselves “out of that loop” was the importance of seeking help from formal supportive services in the community and/or health care professionals. As one caregiver advised another group member: “If there are services out there, ask for it. This makes you bold, caregiving. Just call.” Over the four-month observation period, every support group in the study witnessed at least one example of a new participant who sought assistance from formal supportive services and returned to the group newly converted to the philosophy of self care. Clarice's experience is typical in this regard. Having previously cared for her parents, she was now caring for her husband, who was 86 and

suffering from dementia. At her first support group meeting, she shared her frustrations about taking care of her husband and her reservations about seeking help: “I’m very angry. By the time this ends, I’ll be an old lady. My years will be have been spent taking care of people. People suggest hiring someone, but I can’t. I’m not working. What would I tell my husband?” Other members of the group encouraged her to bring someone in for just a couple days a week. She explained that she didn’t want to offend her husband and that she felt guilty leaving him: “I know I only have so many years left with my husband. Why see some mediocre movie? I want to be with him.” But at the next support group meeting, Clarice admitted that the discussion had really affected her:

I hated my husband, I hated my life, I hated the disease. I think I realized that I had lost my life. And I was very angry. So I made a big list and I started getting my life back....I hired somebody I know to come to the house twice a week. I told her I don’t know yet what you’re going to do, but I feel like I need someone there so I can be removed one step from everything. I need to be out there doing things.

By framing self-care and self-advocacy as strategies for taking better care of their family members, caregiving discourse validates caregivers’ need or desire to care for their partners or parents, but it also re-casts care provision as something that can be legitimately shared or purchased. In effect, caregiving discourse encourages care providers to see certain aspects of care provision *as work*, rather than “just something one does” for family. This was a critical transition in group identification not because caregivers imputed market value to their carework,<sup>30</sup> but because in identifying care activities that could be shared or purchased, they

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<sup>30</sup> There is a significant literature on the commodification of carework that addresses issues relating to the market valuation of care, including critiques of the tendency to dichotomize the realms of love and money (Folbre and Nelson 2000; Nelson and England 2002; Zelizer 2005), concerns about what happens to care—and workers—when it becomes commodified (Glenn 2000; Hochschild 1983; Nelson 1999), and more recently, the global consequences of the market for paid care as women from poor countries leave their own families to work as care providers in richer countries (Ehrenreich and Hochschild 2002; Hochschild 2003; Hondagneu-Sotelo 2001).

consciously distinguished between their responsibilities as *family members* and their role as *caregivers*.

This can perhaps best be seen by comparing how non-identified family care providers and group-identified caregivers described their caregiving roles. Family care providers who did *not* identify as “caregivers” typically made no distinction between their familial and caregiving roles. Asked if they associated with the term “caregiver,” these respondents gave answers such as:

“I think of it as she’s my mother. ...[T]aking care of her is like taking care of me. And there’s no difference. There’s not a caregiving situation.”

“Being married is like caregiver’s written in there. So I guess that’s about it.”

“No, I’m just his wife, you know?”

“I’m more than a caregiver. I’m their only daughter. I’m their everything.”

By contrast, self-identified caregivers explicitly associated their identification *as caregivers* with a *disassociation* from their familial role. Gabriela, who at the time of this study was caring for her husband, was typical in this regard:

I took care of my mom. My mom had cancer. Okay, I took care of her ‘till the end. My dad had Lou Gherig’s disease, and I just figured it was part of my duty. And there again, when my husband started ... I thought oh, I’m home, I’ll stop working ... that’s my duty. So I just figured it was a duty. And not until the [support group] did it make me aware. Now, it’s not my [duty], you know ... I’m a caregiver! Yeah!

Similarly, when I asked Doris when she began associating with the term “caregiver,” she replied: “Probably when I started the [support] group. Prior to that he was my husband. These were things you did. These were things you put up with.”

Thus, by characterizing long-term care provision as work that is above and beyond the “normal” obligations of a partner or adult child, caregiving discourse validates the efforts of

family care providers—making visible those tasks that are often discounted by family care providers as “just something one does” for a family member. But it also demarcates a clear distinction between one’s familial role and one’s role as a care provider. In this way, caregiving discourse bridges two paradigms for understanding the responsibilities of care: it affirms the belief in taking care of one’s own, but it also introduces a more publicly-oriented understanding of care, one in which caregivers are seen as performing a valuable service that is entitled to both recognition and community support.

Exposure to the discourse of caregiving was a critical factor in whether—and when—family care providers in this study appropriated the caregiver group identity. To understand and adopt the values and beliefs about care provision embodied in the caregiver group identity, caregivers typically required sustained contact with caregiver discourse: participation, for example, in the six-week caregiver class offered by the LA Caregiver Resource Center, or through ongoing care assessments or therapy with social workers or, most typically in this study, regular participation in support groups. The design of this study—selecting interview participants primarily (although not exclusively) from caregiver support groups—meant that most participants were already familiar with caregiving discourse when my interviewing began. But in tracing how long and what form of contact caregivers had with social services, it was evident that care providers who were more familiar with caregiver discourse were more likely to collectively identify as family caregivers. As Table 1 below illustrates, of the 79 caregivers interviewed in this study, 52 identified with the caregiver group identity. All but one of these caregivers were regular attendees of a support group.

TABLE 1: RELATIONSHIP BETWEEN GROUP IDENTIFICATION AND SUPPORT GROUP PARTICIPATION (N=79)

	Group Identified Caregivers	Non-Group Identified Caregivers
Support Group Participation	51	15
No Support Group Participation	1	12

These participants retrospectively attributed their group identification to support group participation or other regular contact with social services. For example, at the time of her interview, Mary, a relatively new caregiver for both of her parents, had attended a support group for about two months. She attributed her identification with the caregiver identity—and the transformation in how she understood the responsibilities of caregiving—to her recent participation in the support group:

You know, I used to think we're the kids and that's just the way it is, and now I use that term [caregiver] a lot. Since I'm gone to the [support group,] I've learned that there's a need for when people get elderly, somebody to be caregiver. Not necessarily a family member, or if it is a family member, yes they are the caregiver. ... Up until this, I never thought about it. I thought well, we'll just take care of them the best we can, however that is. And do what we need to do.

Of the 27 interview respondents who did not group identify, more than half (15) had never attended a support group or participated in any significant way in social service programs or classes. The rest of the nonidentified caregivers had either recently made contact with supportive services,<sup>31</sup> or were caregivers whose family members were institutionalized or did not otherwise need a lot of physical care. These so-called “secondary caregivers” often expressed

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<sup>31</sup> Most had attended a support group three or fewer times.

ambivalence about whether they were “really” caregivers at all, and were much less likely to group identify.

If caregivers’ retrospective accounts tell us something about *when* they began to identify as caregivers, we still need to understand how collective identification affects the politicization of family caregivers. How, in other words, do group-identified caregivers come to question their taken-for-granted assumptions about public and private responsibilities for long-term care provision?

### *C. The Politicization of Collective Identity*

Unlike traditional characterizations of politicized identities, the caregiver identity does not posit a clear in-group/out-group opposition that attributes blame for caregiving dilemmas to particular groups or social institutions. Indeed the most salient boundary in caregiver identity construction is not so much a boundary between oneself and *others*, as it is a distinction between one’s role as partner or adult child and one’s role as a caregiver. In addition, because processes of group identification take place primarily in social services, where professional and legal/organizational norms often proscribe overt “political” activity, there are typically few actors to help link individual problems to structural or socio-cultural causes. But if political consciousness-raising was not the stated goal of social service providers, processes of group identification occurring in the social service context nevertheless produced many of the same outcomes as more strategic political consciousness-raising efforts: processes of group identification (1) emphasized similarities in the experiences of family care providers, (2) re-framed individual care dilemmas as problems shared by caregivers as a group, and (3) highlighted the underlying structural or cultural factors which make long-term care provision

difficult for many families. In what follows, I elaborate these processes in the specific context of support group participation.

Unlike consciousness-raising groups of other organized movements which seek to deliberately frame participants' experiences in ways that emphasize the structural causes of individual discontents, professional and legal/organizational norms in social services mediated against promoting an overt political agenda in caregiver support groups. "I personally ... will say ... if it starts being completely focused on politics, that I don't think it's appropriate to discuss ... particular personal politics," one facilitator observed. "I definitely discourage that, because it takes the focus away from what we're really there for." What caregivers are "really there for" is, according to social workers, emotional support and information. Social workers who facilitate these groups typically see their role as providing a space for caregivers to give and receive advice about changing individual behaviors, including strategies to reduce feelings of stress, guilt, fear, and inadequacy; facilitators generally veer away from observations about the institutional or structural causes of caregiving strains. While the facilitators interviewed for this study acknowledged that "political" issues sometimes come up in caregiver support groups—e.g., prescription drug costs, Medicare, Medicaid, and, during the November 2004 California election, stem cell research—most said they avoided, and at times actively discouraged such discussions. Some social workers explained that there wasn't enough time to talk about political or systemic issues when so many caregivers had more pressing personal issues to discuss. But several facilitators also suggested that professional norms and/or organizational prohibitions dictated that they steer discussions away from political topics:

I think it comes from two sources. One is just Social Work 101, you know, we're not supposed to bring our own stuff into group. And the other thing is we're a nonprofit organization and we're not allowed to make any kind of political stands

unless it's clearly like a pro-caregiver issue. But not a political issue. You know what I'm saying?<sup>32</sup>

The training that the Alzheimer's Association gave us as facilitators was very clear: it's not up to us to give them the answers. And it's not up to us to decide what direction the group goes in. And I try very hard to observe those guidelines. Partly because that's part of the affiliation agreement, but partly because I agree with them. It is hard sometimes to sit there and avoid shaking somebody and say "Don't you get it?!" [laughs] And that's ...not an unusual frustration.

If these structural constraints prevented social workers from explicitly politicizing care dilemmas—by, for example, linking participants' problems to particular political institutions or agendas—processes of group identification nevertheless played this consciousness-raising role. Three aspects of group identification were especially noteworthy: the recognition of commonalities among care providers, the re-framing of individual care problems as collective problems, and the identification of the underlying structural or socio-cultural factors that make long-term care difficult for family care providers

First, identification as a caregiver involved recognizing commonalities among family care providers. As Suzanne Mintz of the National Family Caregiver Association observed: "Sure, there are differences if you're a single mom caring for a kid with some congenital thing that you can't even pronounce, or if you're caring for your dad with Alzheimer's disease. The day-to-day things are different, but the emotional issues are the same. The difficulties in dealing with unresponsive systems [are] the same." For many caregivers in this study, one of the most memorable moments of joining a support group was the discovery that other people were experiencing similar problems. Gabriela, who was caring for her husband, recounted the first time she attended a support group meeting:

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<sup>32</sup> For an opposing view on the responsibility of social workers to "talk politics" see Breton (1995).

When I first went in there I was a basketcase. I mean, just hearing everybody share what was going on? I just started to cry. I just thought, my god! I'm not in this alone! We're all in the same boat, one way or another, you know?

Jackie recalled that she did not consider herself a caregiver for her husband, nor did she realize how stressful her care situation had become, until an acquaintance convinced her to attend a support group meeting at the LA Caregiver Resource Center.

I really wasn't that interested. But I did go to the meeting. And I laughed when I told [my friend], I said I didn't know I had a problem until I went to that meeting! I'm doing the same thing they're doing!

Despite the fact that care providers were often dealing with different diseases<sup>33</sup> and levels of dependency, and despite often dramatic disparities in access to resources and support networks, caregivers repeatedly emphasized the similarities in their experiences: "I'm amazed that even though we might have nine or ten people at a meeting," observed one man, caring for his wife, "all of us have different problems, yet they're all related."

Small-group solidarity, of course, is different from a sense of belonging to a larger collectivity or constituency, and it is here that a second aspect of group identification with the caregiver identity played an important role in shifting participants' consciousness from the individual to the collective level: support group participants' use of caregiving discourse *generalized* the dilemmas of family care providers. Thus, in addition to emphasizing the commonalities among individual support group participants, caregiving discourse portrayed caregiving problems as *endemic to all people occupying this structural position*. Support group facilitators, for example, typically responded to individual problems raised in the group by recasting them as problems common to *all caregivers as a group*:

"It's common for you and for all caregivers to stop taking care of yourself."

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<sup>33</sup> While dementia is most frequently associated with Alzheimer's disease, it is also associated with Parkinson's disease, vascular disorders, strokes, head injuries, infections, drug use, and nutritional deficiencies.

“As caregivers, how do we deal with that?”

“It’s important for caregivers to realize that whatever you’re giving, is good enough.”

The following support group interaction illustrates how group members and the facilitator together recast one individual’s situation as a collective problem: Doris was caring for her husband, whose Alzheimer’s had made him both paranoid and extremely combative. Two months into the observation period, she was hospitalized for a bleeding ulcer. When she returned to the group and described what had happened, participants around the table cried out: “That’s the stress!” and “That’s from caregiving!” The facilitator waited for things to quiet down and then said to the group: “See how she puts herself last because she’s caring for her husband? That’s what caregivers do.”

By identifying with caregivers as a group, participants were able to extrapolate from their personal experiences with the health care system, supportive services, or government entitlement programs to see their experiences as common to anyone trying to provide care for a family member with a chronic disease or disability. Carolyn’s description of trying to obtain disability benefits for her husband is typical: “You know, you fill out those forms and you’re trying to figure out, I mean they’re so difficult! And you think how could a person, for instance, who *doesn’t* have a master’s degree or *doesn’t* speak [English], how do they do these things? How do they? I would think that they just give up. It is so complicated.” Such expressions of solidarity with other caregivers were common among group-identified participants, and reinforced an understanding of caregiving problems as *collective grievances*.

Finally, by re-casting individual problems as problems common to caregivers generally, group identification highlighted the structural or socio-cultural factors that made long-term care

so difficult. “The point is, it doesn’t have to be this hard,” observed Susanne Mintz of the National Family Caregiver Association, describing this recognition. “It’s hard. It’ll always be hard. But it doesn’t have to be this bloody hard. And one of the reasons it’s so bloody hard is because the systems are just not set up to be friendly to caregiving families. ...It’s not you, it’s *it*.”

The relationship between collective identification and recognition of underlying systemic problems was striking in this study. Group-identified caregivers were much more likely than non-identified caregivers to attribute long-term care dilemmas to structural or socio-cultural problems rather than individual failings. Of the 52 respondents interviewed who expressed a clear identification with caregivers as a group, all but one identified institutional or cultural factors that exacerbated the difficulties of providing long-term care. By contrast, of the 27 care providers who did not identify with caregivers as a group, only 5 attributed their caregiving problems to structural rather than individual conditions. (This number drops to 3 when caregivers who worked in the health professions—and who explicitly attributed their structural understanding of long-term care provision to their work—are removed from the sample of non-identified caregivers).

The structural explanations for long-term care dilemmas that emerged from processes of group identification fell into five broad categories: (1) *fragmentation of long-term care services and information*—including references to how difficult it was for families to find information about supportive services and financial assistance for long-term care costs; (2) *changing demographics*—including observations that the combination of longer life expectancies and changing family structures (e.g., more single-parent families, more adults in the paid labor force, more “sandwich generation” families in which adults are simultaneously caring for dependent

parents and dependent children, and more family members living farther apart) made long-term care provision more difficult than it has been in the past; (3) *social values about care for the sick and elderly* – including observations that Americans do not respect the elderly as well as other countries or that current generations do not care for their elders in the same way that past generations did; (4) *health care costs* – including references to the high cost of prescription drugs, supportive services, and nursing home care, and observations that such costs are not covered by most health insurance plans; (5) *government responsibilities for long-term care*— including references to the lack of coverage for long-term care expenses under Medicare, overly strict eligibility requirements for Medicaid long-term care assistance; and government funding priorities.<sup>34</sup>

While all of these frames identify institutional and socio-cultural factors that exacerbate the problems faced by family care providers, it is notable that with the occasional exception of the government responsibility frame, most lack a specific blameworthy target. Explanations that emphasized fragmentation of care, demographic changes, social values and long-term care costs all highlighted cultural and structural problems but rarely identified particular institutions or groups that bore responsibility for causing—or remedying—those problems. Respondents who attributed caregiving dilemmas primarily to health care costs more frequently blamed institutions such as pharmaceutical companies and health insurance companies, but very rarely targeted those institutions with the responsibility for remedying caregiving dilemmas. The costs of health care were often characterized as a macro-level problem, which no one institution or group of institutions could ultimately fix. As I discuss in the next chapter, the only context in which respondents linked their situations to a specific, blameworthy actor—and an injustice framing—

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<sup>34</sup> At the time of this study, concerns about state funding priorities were often tied to a criticism of the American war in Iraq.

was in the case of Medicaid eligibility, where respondents decried the fact that the government provided long-term care assistance only to those people who met the strict means test for eligibility.

Without a framework that attributes causal or remedial blame to specific actors or institutions can we say that collective identity has in fact been politicized? Indeed one could argue that identifying structural explanations for which there is no apparent cause or remedy is more likely to lead to *de*-politicization than collective action. But it is here that the nature of the movement itself is relevant. In conflict movements, oppositional consciousness is conceptualized as an understanding of the differential status and power of groups in society (Mansbridge and Morris 2001; Taylor and Whittier 1992). By contrast, with issues that lack a blameworthy opponent, such as health security, the role of collective identity in developing oppositional consciousness is *not* to specify relationships of inequality or subordination, but to challenge longstanding norms about the distribution of public and private resources by (1) defining a group's needs or interests as legitimate matters of public, rather than private, concern and (2) demarcating a constituency as deserving beneficiaries of public resources. The following section illustrates both effects of collective identification on the oppositional consciousness of study participants.

#### *D. The Effects of Collective Identification on Oppositional Consciousness*

Collective identification had two primary effects on the oppositional consciousness of family caregivers in this study. First, group-identified caregivers were more likely to formulate long-term care dilemmas as matters appropriate for public policy intervention. Second, group-

identified caregivers were much more likely to describe themselves as *deserving beneficiaries* of government help.

In this study, family care providers who did not collectively identify as caregivers largely attributed their caregiving problems to their own personal or family circumstances. As a result, they rarely considered how other families could be similarly affected or how those problems might be redressed through public policy. Linda, for example, was caring for her mother, who had been diagnosed with Alzheimer's. A full-time professional, Linda depended on adult day care to be able to continue working. Her comments on the affordability of adult day care are typical of family care providers who did not identify with caregivers as a group.

I'll tell you, if my brother weren't paying the bills, I couldn't afford [day care]. I just don't know what I would do. I wouldn't be able to help. I wouldn't be able to help take care of my mother.... You know, I really don't mind paying, but their price is so high, that it's really beyond what I can pay. You know? I would never ask somebody else to pay my bill for me, but this, this has me over a barrel. If my brother were not taking care of this, I would be so out of luck. Really out of luck.

The individualized way in which non-identified caregivers spoke about caregiving problems contrasts sharply with those identified as caregivers. When family care providers saw their problems as *common to caregivers as a group*, they were much more likely to articulate expectations for policy intervention. Toni, a group-identified caregiver for both her parents, struggled with many of the same issues regarding the affordability of day care as Linda, but she explicitly framed those issues as matters of public policy:

My feeling is ...that the government knows that the Alzheimer's people can bring down the health services in America. I said that to my husband from the beginning, I said I know they're going to ...be pushing for Americans to keep these people at home. ...But there's no facilities! I mean it's just unconscionable that the government is not running [Alzheimer's day care facilities]...They run [children's] day care, and Alzheimer's care is needed just as much as [children's]

day care....There's a very real need for quality day care with Alzheimer's patients.

Similar patterns in the ways in which non-identified and group-identified caregivers spoke about caregiving dilemmas could be seen in comments about a wide range of long-term care issues.

Consider the following representative comparisons:

#### *RESPITE CARE*

*Not Group Identified:* Respite care never was an issue for me because I just felt that it was part of my job, and I never looked upon you know, I need to get away from my mother.

*Group Identified:* I think [respite] should be incorporated in any MediCal or senior, elderly health care plan. A choice of getting some kind of respite and good care for them while you are getting respite. I think that's so important. I see it so much right now, that the caregiver needs an outlet. And it's not available to you. It's not readily available to you....And if it is, you can't afford it probably.

#### *MEDICAID ELIGIBILITY*

*Not Group Identified:* Well it wasn't until my mother was destitute that I was able to tap into any government resources. And I felt that you know, I really needed help prior to that because I just had to wait until she had nothing left to qualify. And I spent a lot of sleepless nights worrying that you know, I'd have to spend every thing she had on a nursing home.

*Group Identified:* I don't think it's fair that the government should expect its citizens to be drained of everything they've acquired until they are reduced to the house they live in, a car to drive, and \$19,000 in the bank. Big deal. ...You're now at a poverty level.

With regard to each caregiving issue, non-identified caregivers spoke of their caregiving problems in terms that reflected hegemonic norms about long-term care provision as a private, family responsibility. By contrast, group-identified caregivers not only spoke of each issue as a *group problem*, but they expressed a normative expectation that the problem was appropriate for policy intervention.

This re-conceptualization of caregiving problems as legitimate matters of political contestation was contingent on processes of group identification: in the absence of collective identification, care providers had no frame of reference for evaluating whether their care dilemmas were common to others and hence no way of identifying systemic problems in long-term care provision. Focused exclusively on the internal needs of their family, they were unlikely to see care provision as a collective problem that could be remediated through public policy.

The second way in which collective identification influenced oppositional consciousness could be seen in the self-presentation of caregivers as potential beneficiaries of government assistance: Group-identified caregivers were much more likely to describe themselves as *deserving beneficiaries* of government help. Very few caregivers in this study actively *opposed* government assistance for long-term care, but non-identified caregivers tended to offer weak justifications for government assistance. They were less likely to suggest specific ideas for policy reforms, for example, and instead spoke more generally of government “help.” Non-identified caregivers were also less likely to speak in strong normative terms about state intervention; they rarely talked about what the government “should” do or “ought” to do, and instead relied on more passive phrasing—suggesting, for example, that it “would be nice” if the government helped families with long-term care provision. By contrast, group-identified caregivers, as the above quotations illustrate, were far more likely to hold definitive opinions about the responsibilities of the state.

These differences in expectations for government intervention correlated closely with how caregivers understood the responsibilities of care: non-identified caregivers tended to describe carework exclusively as a family responsibility, whereas group-identified caregivers

were more likely to describe caregiving as a social contribution deserving of public support. Thus, Ruth, a non-group identified care provider for both her parents, supported the idea of government assistance but said she didn't expect it for her family: "I think the government stuff is lacking. But ...what I haven't done is I haven't expected them to do anything for me. I sort of thought this is a family matter." Similarly, Irma, a non-group-identified caregiver for her mother, said she supported government help for long-term care provision, but qualified her support with the following statement: "It's really... a labor of love. ...I hate to say most Americans are a little bit selfish, and they wouldn't dream of sacrificing their own happiness or their own travel plans to make sure that mom had turkey dinner. ...They're thinking the selfish way, that I'm going to get something for this. This is an act of love and commitment and character really."

While group-identified caregivers demonstrated an equally strong commitment to family duty and responsibility, recall that most group-identified caregivers saw carework as something *above and beyond* the normal responsibilities associated with a familial role. As a result, group-identified caregivers were more likely to describe themselves as performing a vital social contribution, saving the government and health insurance companies money by caring for their family members at home. This argument was often articulated in discussions about California's Medicaid program (known as Medi-Cal), which provides long-term care benefits to the very poor. "The alternative [to family caregiving] is that they go on Medi-Cal and then they're paid for," observed one caregiver. "So you're actually doing a social service by taking care of your own people." By caring for their family members at home rather than institutionalizing them

(and, implicitly, turning to Medicaid for financial assistance)<sup>35</sup> these caregivers saw themselves as *deserving* some form of public support: “I think basically caregiving needs help,” observed one caregiver articulating this point. “If you’re really thinking about people placing their loved ones in nursing homes and you’re talking about [\$50,000] on up to \$70,000 a year, and the states are paying for this through one way or another, isn’t it far better to allocate moneys into the system to compensate caregivers themselves up to a mere fraction of what [the state would otherwise pay]?”<sup>36</sup>

Others inverted this argument—rather than articulating the ways in which family caregivers saved society money, they emphasized the ways in which caregivers, when not sufficiently supported, *cost* society money. Janet, who retired early on her doctor’s advice after the stress of caring for both her parents made her ill, observed that it would benefit the U.S. population generally if caregivers were to receive some kind of assistance: “[T]he country really is losing the services of [caregivers] and causing a higher cost because *they’re* getting ill. ... [S]o you’re going to have a lot more illness costs because of the drain on the people that are unable to handle it.” These perspectives shared an understanding of caregivers as making an important contribution—in the health care system, the economy, and society generally—deserving of public support.

Collective identification in this case, then, provided a way for caregivers to see the commonalities in their individual experiences, to see caregiving dilemmas as collective rather than individual problems, and to identify the institutional and socio-cultural factors that made

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<sup>35</sup> In 2000, approximately 40% of nursing home residents relied on Medicaid as their primary source of payment at admission (either because they were already poor or because they had previously “spent down” their assets due to high medical expenses). Another 20% enter nursing homes and subsequently deplete all of their life savings until they are technically impoverished—at which point they qualify for Medicaid coverage (O’Brien and Elias 2004).

<sup>36</sup> For a more detailed discussion of caregivers’ reliance on the principle of deservingness in making claims for state intervention, see Chapter 4.

care provision so difficult. But collective identification did *not* politicize caregivers by establishing an “us” versus “them” binary in which group-identified caregivers saw their own interests as being in some way harmed by particular blameworthy opponents. Rather, collective identification politicized caregivers by challenging longstanding norms about the distribution of public and private resources for long-term care provision—re-defining caregiver needs and interests as legitimate matters of public concern and caregivers themselves as deserving beneficiaries of public remediation.

## V. CONCLUSION

Social movement scholars widely understand collective identity to be a critical component of collective action. Yet our theoretical insights for precisely how collective identity politicizes individuals have largely been premised on research about movements involving social groups who confront clearly-identified opponents. As such, theories for understanding the mechanisms by which collective identity politicizes individuals have shared an emphasis on adversarialism and causal attribution: “we” understand “them” as benefiting from or being responsible for a collectively defined injustice. But in movements that lack a clear “us versus them” binary, where challengers seek to de-construct an ideology that segregates distributional issues as domestic or economic rather than public-political, the role of collective identity is less about defining dominant and subordinate relations than it is about reconceptualizing “private” discontents as matters appropriate for public deliberation and collective remediation.

This chapter has sought to demonstrate specifically how collective identity transforms the way in which individuals think about the private and public responsibilities of care provision. Because caregiving is generally considered a “natural” extension of family roles and because of

longstanding cultural norms about the self-sufficiency of the family unit, care providers are generally reluctant to identify with a caregiver identity that embraces a more public-oriented understanding of care. The discourse of caregiving, as it has emerged in social services and caregiver advocacy organizations, relies on the principles of self-care and self-advocacy to bridge cultural norms about family responsibility for care provision with an understanding of long-term care as a community or social responsibility. Characterizing caregiving as work that is above and beyond the “normal” obligations of a partner or adult child, as something that can be shared or purchased, caregiving discourse simultaneously makes visible and validates the efforts of family care providers, yet challenges longstanding norms about care provision as exclusively a family responsibility. Note that this characterization of caregiving as work “beyond the call of duty” potentially poses significant limitations on the range of care providers who might collectively identify as “caregivers”: it is much harder, for example, to make a case that the “ordinary” care of a baby or a sick child is “overtime” work in the same way that caregiving discourse characterizes long-term care.<sup>37</sup> Why norms about what constitutes the “natural” obligations of a partner or adult child with regard to long-term care may be changing more rapidly or in different ways than norms about the “natural” obligations of parenting is a question that invites serious empirical consideration in the future.

Group identification in this case tended to begin when care providers made significant contact with some form of social services. While most social services typically lack an overtly political agenda, processes of group identification nevertheless had a consciousness-raising component, highlighting similarities in the experiences of family care providers, re-framing individual care problems as collective problems, and emphasizing the underlying structural or

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<sup>37</sup> I am indebted to Myra Marx Ferree for raising this point.

socio-cultural factors that make long-term care difficult for families in the United States. But the influence of group identification on the oppositional consciousness of study participants was not to attribute blame to specific targets or opponents, as in more traditional understandings of collective identity, but to define the issue of long-term care provision as a public problem appropriate for policy intervention, and to portray family caregivers as deserving beneficiaries of public resources.

The debate over how the responsibility for long-term care is framed—as a private-domestic, or public-political matter—is fundamentally an ideological debate about the distribution of private and public resources. To the extent that long-term care continues to be understood as the “natural” or “normal” responsibility of families, the costs of long-term care provision remain exclusively in the domestic sphere. In this paradigm, because caregiving needs are largely met by family members, there is no need for public policies involving long-term care. As Lynn Feinberg, Director of the National Center on Caregiving observed, “Why should we use public dollars to pay for something that family members, mostly wives and adult daughters, will do for free?”

But to the extent that long-term care is understood as a legitimate political concern, policymakers are forced to find solutions to the problems of care provision. For many policymakers, this move from the domestic to the public sphere is viewed as potentially explosive. Gail Hunt, Executive Director for the National Alliance for Caregiving in Washington, observes that all policymakers “basically believe that they need to be supporting caregivers because they understand that caregiving is the unpaid extension of the health care system. They just don’t want to have to support them too much.” As the problems of long-term care provision spill over from the domestic sphere into the political sphere, policymakers are

beginning to consider both market and state-funded solutions. How aggressively policymakers pursue these solutions, and what types of solutions emerge from political contestation, will likely depend on the extent to which family care providers see themselves as a constituency with needs that demand political intervention.

### CHAPTER 3

#### INJUSTICE FRAMING IN THE ABSENCE OF A RESONANT SOCIAL RIGHTS FRAME

*There are in general two quite distinct kinds of moral transaction. On the one hand, there are gifts and services and favors motivated by love or pity or mercy and for which gratitude is the sole fitting response. On the other hand there are dutiful actions and omissions called for by the rights of other people. These can be demanded, claimed, insisted upon, without embarrassment or shame. When not forthcoming, the appropriate reaction is indignation; and when duly done there is no place for gratitude, an expression of which would suggest that it is not simply one's own or one's due that was given.*

—Joel Feinberg (1966, p. 143)

Social movement and sociolegal scholars generally agree that a necessary condition for challenges to existing social and political conditions is an *injustice framing*, a way of redefining “as unjust and immoral what was previously seen as unfortunate but perhaps tolerable” (Snow and Benford 1992, p. 173). The discourse of rights is widely understood to be a powerful tool for “naming” (Felstiner, Abel and Sarat 1980-81) harms or injustices and making claims for remediation. Rights evoke images of durability, of a permanent commitment by the state and, implicitly, society, and it is this allure of stability and inclusion that makes rights seem valuable to people who do not possess them. Yet it is also their malleability, their capacity to be repossessed and reimagined that draws so many people, with such widely varying interests, to the struggle for rights (Hartog 1987).

The prevalence of “rights talk” in contemporary American political discourse, however, belies its limitations as a way of framing injustice. We know that rights are not, in fact, infinitely malleable, that there are cultural and political limits beyond which rights claims are no longer resonant or meaningful as a way of interpreting one’s experiences or social conditions (Gilliom 2001; Hull 2001; Polletta 2000). Nowhere are these limitations more visible than in the area of

social welfare. Where rights discourse has proved useful as a source of injustice frames for a wide range of issues involving individual freedom and political and social participation, its utility in framing injustices involving health and economic security has proven far more tenuous. In contexts involving relationships of care and dependency, which have historically been viewed as the responsibility of private families rather than the state, Americans are particularly ill-accustomed to thinking about having “rights” to state provision (Fraser 1989b; Gordon 1994). Recent survey research has found that few family caregivers in the United States conceive of their work as a “public” issue involving rights; indeed many *reject* such a characterization outright (National Family Caregivers Association 2001). The failure of a social rights discourse to widely resonate with Americans raises important questions about how political demand for new social entitlements is created. In other words, how do individuals develop oppositional interpretations, or injustice framings, of longstanding “private” social practices, without recourse to a resonant social rights discourse in which long-term care is envisioned as a public responsibility?

In Chapter 2 I argued that individuals who collectively identified as family caregivers were more likely to identify structural or cultural explanations for why care provision is so difficult for American families. While most of these explanations lacked a specific, blameworthy target, some caregivers did attribute specific responsibility to the government. In this chapter, I more closely examine this group to identify (1) how individuals develop injustice framings about care provision that assign blame or responsibility for care dilemmas to the state; and (2) how the claims that emerge from processes of injustice framing influence understandings of what kinds of care needs rise to the level of “rights” and “entitlements.” In the next section, I lay out a theoretical framework for tracing processes of injustice framing and the construction of

new cultural understandings of rights. In Part II, I elaborate the precise coding strategies I used to analyze the data for this chapter. In Part III, I examine how individuals come to reinterpret or name previously tolerable caregiving conditions as harms or injustices, how they identify a target responsible for the injustices, and how they conceptualize a remedy for ameliorating their conditions. I then consider the relationship between the claims that emerge from these processes of injustice framing and caregivers' understandings of what rights "mean" in the context of long-term care.

I find that virtually all caregivers in this study maintained strong commitments to norms about family provision of long-term care. Most caregivers who relied exclusively on the hegemonic family responsibility frame for understanding their circumstances entertained little to no consciousness of social welfare rights in the context of long-term care. By contrast *grievants* in this case—those who relied on injustice frames—held a more expansive understanding of the meaning of "rights," one that included state-funded benefits and services for care provision. But while claims for state intervention challenged dominant cultural norms about care as exclusively a family responsibility, these claims were constrained by the oppositional frame with which their grievances were formulated.

The most significant source of oppositional interpretations about care provision in this case was the state's Medicaid program, a public assistance program that assigns primary responsibility for care provision to the family, and distributes long-term care benefits only on the basis of need. I argue that this *needs*-based conceptualization of state intervention resonated with caregivers because it integrated expectations for state assistance with beliefs in the primacy of family responsibility for care. By contrast, a social insurance conceptualization of state intervention was less resonant among these caregivers because it positioned primary

responsibility for care with the state rather than family. The need-based claims that emerged from processes of injustice framing represent, I argue, a passive form of political demandmaking, lacking the political authority Americans have long associated with rights-based claims to state intervention.

### *I. INJUSTICE FRAMING IN THE SOCIAL MOVEMENT AND SOCIOLEGAL LITERATURES*

In this chapter, I draw on two parallel theoretical frameworks for studying injustice framing: the social movement literature, which emphasizes the use of discourse as a way of mobilizing individuals toward collective action (Snow et al. 1986; Snow and Benford 1988; Steinberg 1999), and the sociolegal literature on legal mobilization, which emphasizes the processes by which individuals invoke legal norms to make sense of events and experiences, delegitimize conduct accepted as natural or normal, and to define what is just, appropriate, or legitimate (Engel and Munger 1996; Galanter 1983; Lempert 1976). While the two frameworks focus on different outcomes for grievances, discussed below, they both offer analogous ways of conceptualizing how individuals “name” injuries or see harm where none existed before, and in what follows I discuss them together as a single approach to studying grievance construction (cf., Marshall 2003).

Turner and Killian (1987, p. 242) famously observed that a social movement “is inconceivable apart from a vital sense that some established practice or mode of thought is wrong and ought to be replaced.” For many years, the dominant explanations for political and legal mobilization emphasized the importance of eliminating barriers to participation and providing sufficient incentives to encourage participation. In this paradigm, researchers understood grievances to be *ubiquitous*; their analytical focus was on the cost/benefit

calculations for the mobilization of grievances rather than how individuals interpret their experiences as grievances in the first place (Jenkins and Perrow 1977; McCarthy and Zald 1977). More recently, theorists have expanded their scope of inquiry to consider the decision processes shaping how individuals understand and evaluate their circumstances (Gamson 1992a). Today most would agree that mobilization requires, at a minimum, an interpretation of existing social conditions, practices, or modes of thought as *unjust* or *injurious* (Gamson 1992b; McAdam 1982; Moore 1978; Turner and Killian 1987). In a seminal article on the emergence of disputes, William Felstiner, Richard Abel, and Austin Sarat (1980-81, p. 635) observe that “naming” a problem—saying to oneself that a particular experience is in some way injurious—is a critical transformation: “Though hard to study empirically ... the level and kind of disputing in a society may turn more on what is initially perceived as an injury than on any other decision.”

Social movement theorists have relied on the concept of *collective action frames* to understand the work of redefining as unjust what was previously seen as acceptable or tolerable (Snow and Benford 1992, p. 173). Collective action frames refer to sets of beliefs and meanings that shape our understandings of our circumstances, including what kinds of action are imaginable, which targets are appropriate for blame, and what political concepts (such as rights) may be employed in a given context. *Legitimizing frames* are interpretations that largely reflect and reinforce the status quo; they have a taken-for-granted quality, an inevitability or naturalness that leads to acceptance, rather than critique of one’s circumstances. (Gamson, Fireman and Rytina 1982) By contrast, *oppositional*—or *injustice*—frames are interpretations of experiences or conditions that support the conclusion that some moral principle has been violated and ought to be redressed. William Gamson (1992b; 1995; 1982), who has perhaps most famously elaborated the concept of the injustice frame, observes that people do not necessarily choose

between legitimating frames and injustice frames, but may hold both to some degree, using these in different contexts to make sense of their circumstances and justify their actions or those of others.

The social movement framing and sociolegal literatures on grievance construction suggest that to generate discontent among potential supporters, an injustice frame must accomplish three tasks. First, it must emphasize—or “name” (Felstiner, Abel and Sarat 1980-81)—the harm or indignity that has occurred. Gamson argues that to inspire mobilization, the evaluation of harm must be something more than a cognitive or intellectual judgment about what is equitable; rather it must be a *hot cognition*, “the kind of righteous anger that puts fire in the belly and iron in the soul” (1995, p.91). “Naming” an injury, then, requires attention to the emotional valence attached to an individual’s perception that some standard or principle has been violated. Social movement scholars generally understand anger and indignation to be *high activation* emotions, motivating people to challenge the conditions that they perceive as injurious (Britt and Heise 2000; Jasper 1998). By contrast, emotions such as shame or guilt or embarrassment are considered *low activation* emotions, tending to paralyze rather than mobilize individuals to act (Taylor 2000). The quality or degree of emotions individuals attach to social conditions depends in part on what or who they perceive to be responsible for the injury (Ferree and Miller 1985).

Thus, the second task of the injustice frame is to provide a target against which these emotions can be usefully vented—what Felstiner et al. (1980-81) refer to in their framework for grievance construction as *blaming*. Gamson (1992b) observes that while these targets can be anything from corporations or government agencies to individuals or groups, an injustice frame requires some degree of *concreteness* in the target. To the extent that individuals see only

impersonal or abstract forces as responsible for suffering—nature, society, God, “the system”—they are more likely to accept the status quo and make the best of it.<sup>38</sup> “We may think it dreadfully unfair when it rains on our parade,” Gamson observes, “but bad luck and nature are poor targets for an injustice frame” (1995, p.91). If reification and excessive abstraction act as impediments to grievance construction, so too can *internalization* of blame: people who blame themselves for a situation are less likely to see it as injurious (Britt and Heise 2000; Felstiner, Abel and Sarat 1980-81). Thus an injustice frame must provide people with a way of seeing the cause of their injury as the result of specific, identifiable forces external to themselves (Ferree and Miller 1985).

Finally, the injustice frame must prescribe a remedy—or “claim”—some course of action to ameliorate the perceived harm (Felstiner, Abel and Sarat 1980-81; Gamson 1992b). In some cases this involves demanding remedial action from the person or entity believed to be responsible for the injury. In more complex cases, in which the cause of an injury differs from the actor responsible for fixing it, anger at those causally responsible must be translated into demands for a third party to provide a solution (Jasper 1998). Note that the social movement framing and sociolegal frameworks for grievance construction diverge in their specification of the mode of redress. Whereas collective action frames stress participation in collective action, the sociolegal framework largely emphasizes individual claims for relief (Marshall 2003).

Historically, Americans have relied primarily on the discourse of rights to make claims against the state, in large part because rights claims implicitly embody all three components of an injustice frame: they emphasize harm or injury, articulate a causal theory linked to specific, blameworthy targets, and ask for a remedy (Marshall 2003). Americans are fiercely committed

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<sup>38</sup> Gamson (1995) also warns of the opposite problem: by overly concretizing targets, there is a danger that people will miss the underlying structural conditions that produced the social condition at issue.

(in principle if not in practice) to what T.H. Marshall (1992 [1950]) would call *civil rights* claims (e.g., rights to individual freedom, including freedom of speech, thought, and faith, the right to own property and enter into contracts, and the right to be treated equally with others before the law), as well as claims for *political rights* (e.g., the right to vote and hold office, the right to organize politically). But claims for *social rights*, including rights to health and economic security, occupy a much more tenuous place in contemporary American political discourse (Fraser and Gordon 1992). The notion of social rights in its original sense refers to a reciprocal relationship of responsibilities between citizens and the state: citizens have an obligation to support social welfare, typically through the contribution of funds, and the state is obliged to provide basic welfare to its citizens (McNeely 1998). But in the United States, social rights have historically been contingent not on citizenship status, but on *market participation*. More specifically, the conceptual foundation of the American welfare state was based on a male breadwinner/female homemaker ideal:<sup>39</sup> social insurance programs were designed to protect male breadwinners from the risks—illness, disability, unemployment and old age—that could jeopardize their ability to support themselves and their families, while residual or “welfare” programs were designed to compensate for “family failures,” or families without a male breadwinner—widows, single mothers, orphans (Fraser 1989b; Gordon 1994). Thus, “entitlements” to state provision were attached first and foremost to the individual market participant, while relationships of care and dependency were seen as the prerogative of private families rather than the state—unless “normal” systems of provision break down.

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<sup>39</sup> According to the male breadwinner/female homemaker ideal, men earn a “family wage” sufficient to support children and a full-time wife and mother, and women perform unpaid domestic labor for the household, including care for dependent family members. The male breadwinner/female homemaker model, of course, has never in fact been the reality for many American families—in particular for poor and working class, immigrant, and African American families.

In reality, of course, changing gender norms and patterns of labor force participation have rendered the traditional breadwinner model obsolete. But, importantly, the cultural assumptions underlying what kinds of social welfare claims rise to the level of “rights” or “entitlements” have nevertheless persisted in political discourse: rights-based claims continue to connote (male) independence, autonomy, and self-sufficiency.<sup>40</sup> They are seen as dignified, legitimate, respected claims for state provision (Waldron 1996). By contrast, claims about family “needs”—including care for young children, the sick, the injured, and the elderly—reflect (female) dependency (in the modern-day, negative sense (Fraser and Gordon 1994)); such claims are viewed as stigmatized and suspect—*supplicants*’ claims for state assistance. Thus, while the discourse of rights remains a powerful means of making claims against the state, it is not a discourse that has historically been used to refer to, or successfully advance the collective claims of those with needs for state provision that arise from the “private” duties and obligations of care (see Gilliom 2001). But if “rights talk” does not provide a meaningful, or resonant, way of framing aspects of care provision as *unfair* or *unjust*, how might family caregivers translate their care dilemmas into political demands for future social rights—or state entitlements to long-term care security?

To consider how new cultural understandings of rights can emerge from processes of injustice framing, I draw on Francesca Polletta’s (2000) work on novel rights claiming in the southern civil rights movement. Polletta sought to identify how activists developed “radical yet resonant” claims—rights claims that were not yet recognized in formal law, but which were

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<sup>40</sup> There is a substantial literature in feminist theory that argues that the emphasis on individualism and rationality in rights discourse systematically ignores or underplays the relevance of relationships of care, needs, and interdependency that have been traditionally associated with women (Gilligan 1982; Kittay and Meyers 1987; Noddings 1984; Tronto 1994). These theorists posit a discourse of *care* or *needs* as an alternative to the discourse of rights for understanding experiences related to care and dependence (see Gilliom 2001).

effective in mobilizing people. She found that one of the primary ways in which activists developed resonant rights claims was by integrating rights discourse with other normative languages (see also Primus 1999). Civil rights activists, for example, often merged legal and religious idioms, combining arguments about citizenship and constitutional rights with principles of Christianity and spirituality (see also Sewell 1992). By integrating rights discourse with more familiar ways of talking about the world around them, activists provided individuals with a resonant language for challenging longstanding norms. Polletta's findings provide a key insight into how new understandings of rights, and "appropriate" targets of public intervention, can evolve about care issues formerly considered the exclusive domain of private families: claims for state intervention must in some way be integrated with deeply-entrenched beliefs about family responsibility for care provision.

In the analysis that follows, then, I consider the following questions: In the absence of a widely-resonant social rights frame, how do care conditions understood as unpleasant, difficult, even overwhelming—but for the most part *tolerable*—come to be understood as *harms* or *injuries*? How do individuals redirect the target of their emotions from "bad luck" or "life" toward a specific, responsible actor? And finally, how do the claims for redress that emerge from these processes of injustice framing influence the rights consciousness of grievants, or how they understand what kinds of social needs rise to the level of "rights" or "entitlements"? Can grievances forged in the absence of a resonant social rights discourse ever form the basis of political demands for future social rights? In the following section, I specify the methods used for examining these questions, and then proceed with an analysis of injustice framing among the family caregivers in this study.

## II. METHODOLOGY

To identify the conditions that give rise to injustice framing among family caregivers, I conducted a comparative analysis of the needs, resources, and experiences of caregivers who relied exclusively on legitimating frames in talking about their care circumstances—reflecting the belief that families should care for their own, without the state’s intervention—and caregivers who relied at least in part on oppositional, or injustice frames—challenging norms about family caregiving as *unfair*. I coded fieldnotes from support group observations, taped focus group conversations and interviews for instances of both kinds of frames.<sup>41</sup> Legitimizing frames included references to family “responsibility,” “duty,” and “obligation,” as well as expressions that naturalized the speaker’s circumstances or made them seem inevitable: “That’s life” or “That’s what families do.” For some speakers these were self-conscious statements: “I’m doing this because I’m the oldest daughter” and for some they reflected taken-for-granted assumptions about care: “I’m taking care of mom the way she took care of her own mother.” Injustice frames focused on explicit moral condemnations—“that’s unfair” or “that pisses me off.” Following Gamson (1992b), the words themselves were not sufficient to qualify a segment of conversation as expressing moral indignation; the context also had to make the moral nature of the injustice claim clear. In addition, injustice frames could not be offset by other arguments; when participants qualified their statements by breaking the potential link between an unfairness claim and indignation—“it’s unfair, but...”—the text was not coded as injustice framing.

To analyze the relationship between care needs and injustice framing, I also coded references made by caregivers to *unmet care needs*. These included instances in which caregivers sought assistance with care (typically from market-based supportive services), but

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<sup>41</sup> Note that because interviews offered the most complete analysis of the questions posed in this chapter, descriptive statistics refer only to the interview sample (79 participants).

encountered obstacles to successfully obtaining help. Obstacles ranged from lack of information about where to find assistance, to concerns about affordability, service quality, and accessibility. Because I am focusing here on the construction of political demand for public policy reform, I emphasized only unmet care needs that could be redressed through public policy. There are also well-documented (see, e.g., Abel 1991; Brody 2004) emotional obstacles to obtaining formal care for a family member that are arguably more difficult to remedy through public policy, and these were not coded for analysis. It should be noted that given the perceived social stigma associated with being “bad” caregivers, there is reason to believe that some people may have withheld information about their inability to meet the care needs of their family members. As such, it is likely that the incidence of unmet care needs among participants is actually *higher* than that reported by participants in this study.

Finally, to assess how legitimating and oppositional frames related to the meanings caregivers ascribed to the concept of “rights” in the context of care provision, I also analyzed the data for evidence of and variation in *rights consciousness*—how caregivers interpreted and used the language of law and rights in their everyday lives (see Ewick and Silbey 1998; Merry 1990). I coded all references to legal ideology, specific laws, government entitlements, and “rights talk.” Interview subjects were also asked at the end of their personal interviews a targeted rights question: “If someone from another country were to ask you what rights family caregivers like yourself have in the United States, how would you answer that question?” Where appropriate, some subjects were also given a follow-up probe: “What rights do you think caregivers *ought* to have in the United States?” Answers to these questions, together with other indicators of rights consciousness were analyzed with the data on legitimating and oppositional frames and unmet care needs to assess (1) how caregivers perceived, evaluated, and responded to the dilemmas

raised in long-term care provision; and (2) how the use of legitimating versus oppositional framing influenced the rights consciousness of participants.

### *III. INJUSTICE FRAMING AMONG FAMILY CAREGIVERS*

#### *A. Legitimizing Frames*

In a country in which families provide 80 percent of long-term care (O'Brien and Elias 2004), it should come as no surprise that caregivers in this study uniformly demonstrated a tenacious commitment to the perspective that it was their responsibility or duty as family members to bear the primary burden of long-term care provision. The belief in family obligation is an archetypical example of a legitimating frame: the private provision of care for a family member—no matter what the cost—was understood by most caregivers as the natural and normal thing to do. Indeed for many, the idea that anyone else—and in particular the government—should bear responsibility for long-term care provision was simply inconceivable.

At the time of this study, Vincent was caring for his mother, who had been bedridden for five years following a stroke. Vincent worked full time and cared for his mother before and after work. A Vietnam vet, he joked that caregiving was the most difficult tour of duty he had ever had, but he did it, he insisted, out of a sense of obligation:

Because they brought me into the world, and my mom would do the same thing for me if I came back from overseas shot up or no legs or you know, something god forbid, that woulda happened. But I felt I owed it to her. ...That's what we were brought up with. From the time we were hatched, so to speak, that we were to take care of our older folks.

Asked why he has not hired any assistance with the caregiving, Vincent acknowledged it was partly finances, but also a sense of obligation: “I think family would rather do it themselves. It's a matter of pride.”

By conceptualizing their work as fulfilling a duty to their families, caregivers understood their situations as natural or inevitable. Alex was caring for his wife, who was diagnosed at 58 with Alzheimer's disease. In a discussion with his support group about the challenges of caring for his wife, Alex observed: "It is difficult. .... We've been married 35 years. And I do it because if it was me, I'd know she'd do the same for me." Alex was typical in his matter-of-fact acquiescence: "[T]o me, you just do what you have to do." Larry had given up his home to care for his parents, both of whom had been diagnosed with dementia. Complaining to his support group that his niece and nephew didn't seem to share his values about caring for family, he opines, "Because it's an obligation that they have to do! So you sacrificed your life to move back with mom and dad? So you do it. You just do it. You just make the best of it."

When caregivers experienced frustration or exhaustion or resentment about their circumstances, the family responsibility frame served to mediate those emotions, often transforming them into feelings of guilt or embarrassment. Caregivers felt guilty for not doing enough or for wanting a break, and they felt embarrassed when they admitted they needed help. "I'm not a good caretaker, because of my resentment and anger," a new participant confided to her dementia caregiver support group. "I lose my patience. 'Is today Tuesday?' 'Yes, today is Tuesday.' Then a minute later: 'Is today Tuesday?' 'Yes, today is Tuesday.' And after a while I'm screaming! And you feel terrible. And you feel guilty. And you feel like you're not a good person." In these cases, the family responsibility frame transforms high-activation emotions such as anger and resentment into low-activation emotions—resignation, shame, guilt—simultaneously legitimating and reinforcing norms about family obligations for care provision.

It's important to emphasize that the family responsibility frame was resonant to some extent for *all* of the family caregivers in this study, including those who also adopted more

oppositional perspectives. But what is remarkable here is not the strength of the normative commitment to family responsibility, but the absence of a widely-resonant oppositional frame. Caregivers whose feelings about their circumstances challenged or contradicted the expectations of family obligation, struggled to find a language with which to articulate another view. Barbara's experience in this regard is typical. Caring for her husband had grave consequences for Barbara's emotional and physical health (she was suicidal at one point), her employment status (she was demoted), and her financial well-being (she spent all her savings and obtained a home equity line of credit on her house to pay for supportive services). She says of all of this:

I think we're somehow brainwashed. There's something [about] the way we're brought up in this country. There's no empathy. ... I'll give you an example. ...When my husband was first sick, and my family came up ... my mother said are you having any fun yet? And it's like, do you think cleaning up poop and pee and taking care of a baby who's 50 years old is fun? ... And I think somehow in this country, we're raised that it's your responsibility, you've got to do it. Don't complain and whimper...and then you're rewarded verbally. You know, if you do the job. Oh you're such a good person. Well, no I'm not! I don't like it!

The lack of a widely-resonant oppositional discourse with which to challenge hegemonic beliefs about family caregiving provides a useful opportunity to explore where caregivers derive oppositional frames for "naming" their problems with care provision. In the analysis that follows, I compare the needs, resources, and experiences of caregivers who rely on an injustice frame in talking about their care dilemmas with those who do not, seeking to identify why and how certain individuals come to re-interpret their situations through the lens of an oppositional frame.

*B. Injustice Framing: Naming the Harm or Injury*

Most researchers agree that to (re)evaluate deeply-entrenched beliefs, individuals require some *trigger*—an unexpected event or piece of information that causes them to think about their basic values and how the world diverges from them in some important way (Jasper 1998; Snow et al. 1998). In this case, individuals were unable to evaluate hegemonic norms about family responsibility for care provision unless and until they confronted some disparity between the care they felt obligated to provide and their capacity—financially, emotionally, or physically—to satisfy that obligation. In many cases involving chronic care, particularly for dementia, caregivers reached a point where, for a variety of reasons, they could not personally provide all of the care they perceived to be required by the care receiver. Many worked outside the home on a full- or part-time basis, some had kids to raise, some maintained separate households in other parts of the city, state or country, some had health problems themselves, and most simply needed a break to attend to other parts of their lives. In theory, there are a wide variety of supportive services available to help caregivers with their care needs, such as in-home skilled nursing care, in-home companion care, adult day care, respite care, and nursing home care. But in practice, caregivers confronted a wide range of obstacles to utilizing these services.

According to other research, the most significant reason for unmet care needs in California is lack of information: most caregivers don't know where to turn for help when they need it.<sup>42</sup> Because there is no comprehensive long-term care public policy at either the federal level or in the state of California, the administration and delivery of services and benefits for patients with chronic diseases and their families takes place within a byzantine “system” of state

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<sup>42</sup> A 2003 survey of randomly-selected California state residents who provide care to someone age 50 or over found that two-thirds of all caregivers who wanted education, training or information about services, did not know where to go to get those services (Scharlach et al. 2003). Similarly, three-quarters of caregivers needing financial or legal assistance on care-related issues did not know where to obtain it.

and local agencies, nonprofit organizations, and for-profit businesses. Without a formal gateway to services, the primary challenge for caregivers is simply finding help to address their unmet care needs. Another obvious reason for unmet care needs is cost: supportive services are expensive and are rarely covered by Medicare or private health insurance plans.<sup>43</sup> Medi-Cal, California's health program for low-income families, is the only public program in the state to offer substantial coverage for long-term care services, but because income and asset eligibility standards are typically very stringent, few families actually qualify for benefits. In addition to concerns about where to find and how to pay for supportive services, caregivers also attribute their unmet care needs to the availability of services, particularly for the hours they need assistance, service quality of supportive services, the availability of transportation, and language constraints among service providers.

All of these common obstacles to utilizing supportive services were reported by caregivers in this study, and in virtually all cases, the perception of unmet care needs served as a potential "trigger" for a shift in perspective about care responsibilities. Thus, the "harm" or "injury" in the case of long-term care provision is the belief that care provision is in some key respect falling short, that there are financial, physical or emotional obstacles that caregivers on their own simply cannot overcome. Of the 79 caregivers in the interview sample, 47 (or 60%) described themselves as successfully meeting the perceived care needs of their family members. These caregivers included those whose family members needed relatively little caregiving assistance (typically because their conditions had not yet significantly deteriorated), those who had ample resources with which to find and/or purchase supportive services, those who had significant assistance in care provision from other family members, and those caregivers who

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<sup>43</sup> Private health insurance generally accounts for 5-6 percent of long-term expenditures (Stone 2000b).

obtained supportive services at low or no cost through Medi-Cal. In these cases, caregivers still faced all of the emotional and physical challenges of providing care to a family member with a chronic disease or disability, but they experienced no disparity between the care they felt was their duty to provide, and their capacity to fulfill that obligation. As a result, these caregivers were much less likely to adopt an oppositional frame for understanding their experiences: 32 or nearly 70% of these caregivers relied exclusively on the family responsibility frame when talking about their care circumstances.

By contrast, caregivers who struggled—in many cases unsuccessfully—to satisfy their perceived care obligations were more likely to re-evaluate taken-for-granted assumptions about family responsibility. While their assessments did not always lead to grievances, without the *divergence* between expectations and reality, that initial evaluation simply did not take place. Of the 79 caregivers in the interview sample, 32 (or 40%) mentioned unmet care needs. Of these, all but 6 articulated an injustice framing. Trenton’s experience caring for his 80-year-old wife, who had Alzheimer’s disease, illustrates how the struggle to provide adequate care can trigger a receptivity to seeing care provision in a different light. At the time of this study, Trenton was responsible for cooking, cleaning and maintaining his home, as well as bathing, dressing, and assisting his wife with most aspects of daily living. Like most caregivers in the study, the ethic of family responsibility was the primary frame through which he originally understood his circumstances. “I accepted this not really as a caregiver but just taking over the responsibility in the home that needed to be done. Because I care so much for her, the transition was easy.... [W]hen I see her and think about all of the things that she’s done for our marriage, I never thought of it as a chore.” Midway during the observation period, Trenton began developing chest pains, which he attributed to the stress of caring for his wife by himself 24 hours a day.

His support group urged him to hire some help in the home, and he looked into it, but had concerns about how he'd be able to afford in-home care over a period of many years: “[E]ventually if she lives long enough and the illness persists as a lull...then I would probably have to sell my house. And if I should live five, ten years after she’s gone, I don’t know where I’m going to be.” Trenton eventually did hire someone to help him in the home on a limited basis, and his relief was palpable when he reported this news back to his support group. But he continued to worry about the cost, and those concerns positioned him to re-assess taken-for-granted assumptions about family care provision when he spoke again to his group. Normally, he told his support group, families can take care of themselves. “But then all of a sudden this [disease] comes about and then when it does, it drains [us] so financially....” Trenton revisited this theme in his interview. “[S]omebody within the government in some day in time, they’re going to have to realize that this is almost an impossible situation! There’s no way that you could maintain a comfortable lifestyle without some federal aid.”

The capacity of caregivers to meet their perceived care needs was partly, but not exclusively, tied to income. As Table 2 illustrates below, caregivers with reported incomes over \$50,000 were more than two and a half times more likely to meet their perceived care obligations. Because the sample is nonrandom it is not possible to determine whether these differences are statistically significant, but the findings are consistent with the fact that locating and paying for market-based supportive services requires a substantial amount of resources.

TABLE 2 : INCOME DISTRIBUTION OF CAREGIVERS WITH PERCEIVED AND NO PERCEIVED CARE DISPARITIES (N=75)

Income	Caregivers with Perceived Unmet Care Needs (% of all interview respondents reporting income)	Caregivers with No Perceived Unmet Care Needs (% of all interview respondents reporting income)
< \$30,000	10 (56%)	8 (44%)
\$31-50,000	9 (53%)	8 (47%)
\$51-70,000	3 (27%)	8 (73%)
> \$70,000	8 (28%)	21 (72%)

It should be reiterated, however, that affordability of supportive services was not the only reason cited by caregivers for their inability to provide all the care they feel their family members required: availability and accessibility (i.e., transportation and language) were also notable barriers. Social workers and service providers in this study observed that in Los Angeles, where neighborhoods are highly segregated by race and ethnicity, issues of availability and accessibility were particularly a problem in minority neighborhoods. And in fact in this study, more than three-quarters of Blacks (14 of 17 Black interview participants) and Latinos (7 of 9 Latino interview participants) reported unmet care needs, while only a fifth of Caucasians (10 of 48 interview participants) reported similar care disparities.

If the primary injury or harm in the case of long-term care is the belief that care provision was in some key respect falling short, how caregivers evaluated the discrepancy between their beliefs about family care provision and their capacity to provide that care depended critically on who they blamed for the divergence.

### C. *Injustice Framing: Blaming*

In Chapter 2, we saw that collective identification among family caregivers did very little to specify blameworthy opponents: there was no “us” versus “them” dichotomy by which caregivers could say that their interests were being harmed by another group. But caregivers who did collectively identify were more likely to identify structural or cultural explanations for why care provision was so difficult for American families. While most of these explanations lacked a specific, blameworthy target, some caregivers did attribute responsibility for long-term care to the government. Here we find that the capacity to externalize the blame for long-term care dilemmas was critical to an injustice framing.

To the extent that caregivers in this study *internalized* the blame for their predicaments, they were likely to feel shame, guilt, or embarrassment—low activation emotions that are unlikely to lead to injustice framing (c.f. Britt and Heise 2000; Taylor 2000). Some caregivers blamed themselves for not purchasing long-term care insurance when they had the opportunity. Others blamed themselves for not arranging their finances in ways that would legally qualify their care receiver for state Medi-Cal benefits. Most were just embarrassed that lack of income or poor health would stand in the way of meeting their care obligations to family. In all of these cases, self-blame played a prominent role in *defusing* potential grievances. Belle, for example, had virtually no income at the time her husband was diagnosed with Parkinson’s-related dementia, and for a time, she and her husband were living out of a warehouse they owned. She could not afford in-home care for her husband, and yet could not qualify for Medi-Cal assistance as long as she owned property.

Before we sold the building, our income was \$580 a month. And so that was not much. So our taxes went unpaid and all these things happened. ...We had collateral, so we were not able to get support....we didn’t have enough money for

postage stamps, but they told us we could sell our properties and take care of it. But I guess that's true. We can't expect everybody else to pay our bill.

Similarly, caregivers who blamed impersonal or abstract targets for their frustrations—bad luck or “life”—were more likely to be resigned to the conditions in which they found themselves, with little sense of agency about or awareness of the structural conditions underlying their predicaments (cf., Gamson 1992b). Heidi, who gave up her job and home to care for her mother, spoke of caregiving as a *calling*:

I gave up my life, you know? ... And yes, I would like to go out there and do what I want to do, but you know...when that thing inside you says you have to do something, you cannot serve two masters. ...[E]ither I put her someplace not so nice and say okay, me first. Or I do what my heart tells me to do regardless of what I missed out on. That's my choice. That's what I want to do. And sometimes...this is not what I *want* to do, but this is what I'm *called* to do.

*Anger or moral indignation*—high activation emotions—require an attribution of blame to specific, identifiable forces external to the potential grievants (cf., Ferree and Miller 1985). Where a resonant social rights frame would position the state as a concrete target for frustrations about caregiving dilemmas, the absence of such a frame in American political discourse meant that for most caregivers in this study, the government was not a natural target for blame when they began caregiving. Indeed, many had never considered the role of the state with regard to care provision at all. Asked at the close of their interviews if they thought their caregiving experiences had changed their attitude about the government's responsibilities for long-term care provision, the following responses were common:

I think that probably I've just been so engrossed in managing everything that I really haven't thought a lot about the government's role. (Arnie, 58)

I've never really thought of the government as being part of, you know, my world in that sense. (Susan, 67)

I never really thought about it so I can't really say that my feelings have changed or stayed the same. I guess they've stayed the same, because I didn't really have any. (Elizabeth, 43)

Joan, who for 18 years had been caring for her husband, participated in a peer group discussion about government assistance for caregivers. Silent for much of the discussion, she finally confided to the group that the idea of government responsibility for the costs of long-term care was new to her:

I think...that as a caregiver, we don't feel any entitlement. We never stamp our feet and say this is ridiculous, someone should be paying for this....I mean, I just thought hey, it's the luck of the draw, isn't it? You know? ... But if someone said, you know what? The government ... I mean this whole discussion is like hey wow, that's another way to look at it, isn't it? Someone should be paying for this!

Joan's revelation to the group again highlights the importance of *expectations* in injustice framing: we experience moral indignation only when our expectations for how we should be treated have been violated. But her comment also illustrates how the introduction of an alternative framework can create new expectations, or in Joan's words, a sense of *entitlement*. Where did caregivers derive alternative, or oppositional, interpretations about responsibility for long-term care provision?

A few caregivers found a source of oppositional interpretations in comparisons with countries that offer more state assistance with long-term care provision. Most European countries, as well as Australia, Japan, and Canada offer a wide range of government benefits for family care providers, ranging from free or subsidized home care, adult day care, and institutionalized care to tax credits and direct payment allowances for caregivers (Daly 2001a; Daly and Rake 2003). Several caregivers who used the injustice frame invoked the social norms,

values, and policies of these other countries as a yardstick to measure how the United States fell short. Reba captures this use of international comparisons in this comment to her support group:

Everything is paid for in other countries with things like [day care]. But we don't do that here. ...That's what ticks me off ... [W]e're supposed to be forward thinking? All the other countries in Europe and everywhere else have made ways to do things for their people in the country. But we don't. ... I don't mean that I want everyone to hope the government will pay for everything. I'm saying that there has to be a different attitude about the people in this country. That we need to have some thought given to us.

But if examples from other countries introduced the notion that the state could be held responsible for care provision, they did little to provide a specific, blameworthy target. Because so few caregivers knew details about what other countries provided in the way of long-term care benefits, their comparisons were mostly limited to broad claims about social values and norms. More importantly, their general examples were frequently *countered* by equally general observations from other support group members about the limitations of the health care systems in other countries and the problems faced by citizens there:

Well we know that those socialized countries or some of them, they have a very very high tax rate, much higher than we have. So that's something to look at too, paying for it. (Doris, 59)

I had a coach down at the University of Arizona, his wife had a heart attack over in Hungary. ... [He] told me what he had to go through and from what I understand he said those hospitals over there in some of those countries, you wouldn't go in there if you were dying. (Tony, 73)

In general, participants understood the health care systems of other countries to be so different from that of the United States, that international comparisons ultimately failed to resonate as a meaningful source for oppositional interpretations of caregiving conditions in the United States. As Table 3 illustrates, out of the 41 interview participants who articulated an

injustice frame in this study, only 3 relied on international comparisons as the source of their injustice framing.

Another 5 interview participants, mostly caregivers for cancer patients, drew on their experiences with insurance companies. These caregivers reported constant struggles to obtain coverage for various treatments and services and an ongoing fear that their insurance companies would “drop” their care receiver at their slightest misstep.

TABLE 3: SOURCE AND DISTRIBUTION OF INJUSTICE FRAMES (N=41)<sup>44</sup>

Source of Injustice Framing	Number (%) of Grievants Drawing on Source as Primary Injustice Framing
International Comparisons	4 (10%)
Insurance Companies	5 (12%)
Political or Moral Principles Regarding Care as a Government or Social Responsibility	10 (24%)
Means-Tested Medicaid Program	22 (54%)
Other <sup>45</sup>	1 (2%)

Ten participants, mostly caregivers who identified themselves as “political liberals,” based their injustice frames on political or moral beliefs about the government’s (or society’s) responsibility to ensure the health and economic security of its citizens. Many of these caregivers made a point of observing that these were beliefs they held prior to their caregiving experience. The following comments were common among caregivers in this group:

<sup>44</sup> The categories were nonexclusive, meaning that it was conceivable that an individual could cite more than source of injustice framing. In fact, only one individual, a British citizen who was caring for her mother in Los Angeles, drew extensively on more than one source for her injustice framing—both Medicaid and the comparative case of long-term care in England.

<sup>45</sup> One caregiver articulated a sense of moral indignation about state civil liberty laws, which make it very difficult to institutionalize elders living in unsafe environments.

I think that's an important function of government. I think ancient cultures, ancient civilizations always took care of their old. ... The way [the government doesn't] want to pay for this or pay for that, I think is appalling. (Benson, 67)

I think that's what government is for, for taking care of people. (Lois, 77)

But for a clear majority of grievants (22 participants) in this study, the primary source of oppositional interpretations of care provision was California's means-tested Medicaid program (Medi-Cal). California's Medi-Cal program offers relatively generous long-term care benefit packages for those who qualify for the program, including full prescription drug benefits, and coverage for adult day care, in-home supportive services, and nursing home care. Because the income and asset eligibility levels are so stringent, very few caregivers in this study qualified for any state assistance. But, importantly, *many participants knew of somebody who did qualify for Medi-Cal*. Stories about various Medi-Cal benefits circulated among support group participants and within friendship and neighbor networks, providing not only concrete examples of what the state *could* provide in the way of long-term care assistance, but also creating an expectation among many participants that certain types of services *ought* to be subsidized at least in part by the government. It is typically in conversations about Medi-Cal benefits, that caregivers most clearly articulated an injustice framing.

Susanna was caring for her parents, both of whom suffer from some dementia, her mother quite seriously. Despite working full time, she could only afford to hire a caregiver to stay with her parents for 4-6 hours a day. Her parents were unable to qualify for Medi-Cal benefits, as their pensions placed them just above the eligibility cut-off line. She observes, angrily, in her interview:

I have girlfriends at work say oh, just call up so-and-so, they can help you. [They'll say] my mother has 24-hour care. ... [But] they don't pay a penny because they get on welfare....you have to be poor all your life or whatever, not

work. And then when you're older, you get all the benefits, and that's just not fair! I think that's very unfair. My parents both have worked all their lives, and daddy had two jobs for 16 years. And now he can't qualify because supposedly they make too much money.

Lynne, who was also just above the cut-off line for Medi-Cal assistance, was caring for her husband and mother, both of whom suffered from dementia. Disabled herself and in poor health, she had not been able to secure any state assistance.

I can't get on my knees to wash the floor. ... And so I live in dirt. I'm totally frustrated. The city [sic] had a housekeeping thing that they would pay a housekeeper to come once every two weeks or whatever to help you with that kind of work. Because I have friends who've had it. ... And so I need that, but am I qualified?

Thus where provision of long-term care benefits to the state's poorest residents provided an alternative framework for understanding long-term care provision—one in which families share responsibility for long-term care provision with the state, *the unequal distribution of those benefits to only the state's poorest residents* positioned the state as a blameworthy target for the frustrations of those struggling to meet the care needs of their family members. Tony, a diabetic who is caring for his wife, complained that following his surgery to have both his legs amputated, he couldn't get any government assistance to help pay for somebody to care for his wife.

The guy across the street...he's living over there paying four hundred some dollars a month in that HUD house across the street from me. They got brand new [motorized wheelchairs]. They got everything because they're on Medi-Cal. And [the state] said I can get you a wheelchair, I can get you this. They gave me a number, I called, they said you have Medicare? I said yes. They said you have any secondary insurance? I said I have Healthnet. They said, sorry, we can't help you.

For grievants who began caregiving with little thought to the role of the state in care provision, the experience of seeking solutions to their care problems—most typically their

experience with Medi-Cal—changed the way they understood the relative responsibilities of the family and state for care. Kathrina captures this shift in a story about her friend’s mother, who suffered from severe diabetes and received benefits through Medi-Cal. In her friend’s family, the youngest son lived at home, and due to their low income, he qualified for In-Home Supportive Service payments from the state as his mother’s caregiver. “[T]he son was getting paid by the state to take care of the mom. And I thought, you know, why are they paying you to take care of your parent? It’s ridiculous! The kids should chip in and you should pull together and all this rah rah stuff.” But Kathrina notes that once her step-father was diagnosed with Alzheimer’s, her perception changed dramatically. “When it hit *me*, I thought, oh my God! Where’s the help? [laughs] I don’t know, and I’m thinking you know I pay so much damn taxes! ... I know I pay for the roads and all this stuff that I use, but where’s the help back? Yes, it’s changed my thinking a lot.”

That Medi-Cal—rather than Medicare—served as a key source of oppositional interpretations for caregivers is important here. In many ways, Medicare would seem to be the more likely candidate as a source of injustice frames: Medicare provides for the acute health care needs—and some limited long-term care needs<sup>46</sup>—of most Americans over the age of 65. Not only are entitlement programs like Medicare more respected than means-tested programs such as Medi-Cal, but most study participants or their family members actually *qualified for and received* Medicare benefits. Caregivers could have made the case, then, that if Medicare pays for

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<sup>46</sup> Medicare covers 100 days of care in a nursing facility for those recently discharged from a hospital and who need skilled nursing care or rehabilitative therapy, and provides some home health benefits for those with chronic or disabling conditions who require skilled nursing care following a beneficiary’s hospitalization. Unlike Medi-Cal, however, Medicare provides no assistance for those who need help with personal care (bathing, dressing, feeding, etc.), adult day care, or respite care.

the costs of acute care, it should also do so for chronic diseases like Alzheimer's.<sup>47</sup> But remarkably, *no* caregivers referenced Medicare as a source for their injustice frames.

I suggest that of the two forms of state provision, the underlying logic of Medicaid benefits more closely accords with cultural beliefs about family responsibility for care provision. Social insurance benefits currently represent, in effect, a commitment by the state to *take over* the responsibilities for acute care for all eligible citizens. By contrast, Medicaid assumes that *families* will retain primary responsibility for their own care needs, and the government will step in only when individuals cannot satisfy their basic needs. As I elaborate in the discussion of rights consciousness below, the Medicaid framework arguably resonated more with caregivers than the Medicare framework in large part because it *bridged* caregivers' needs for government assistance with their normative commitments to family responsibility for care. Grievants, in other words, believed that the state had a role in helping families with care responsibilities, *but only when traditional systems of family provision break down*.

#### *D. Injustice Framing: Claiming*

To orient anger or moral indignation toward mobilization, an injustice frame must not only identify a blameworthy target, but must prescribe a remedy, some course of action to ameliorate the perceived injustice (cf., Snow and Benford 1988). Here, caregivers' claims closely tracked the specific care needs giving rise to their grievances. Those caregivers who struggled to afford day care for their care receivers argued for subsidized day care. Those who needed help inside the home argued for tax credits and subsidized home health care. Those who complained about the fragmentation of health services and information about supportive services

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<sup>47</sup> In fact, a few caregivers did make this argument regarding acute care coverage, but with respect to their private, health insurance policies, rather than Medicare.

insisted that the state should create centralized, accessible “caregiver centers,” or that it should fund more social workers to assist caregivers, or provide more information on public television and radio.

While all of these claims directly called for state intervention, it was notable that they were articulated in the language of *needs* rather than rights or entitlements. Caregivers spoke of getting “help” or “assistance” from the state:

[I]f you need the help, the financial help...you should be able to get it...I think just like with children, the government will give you a subsidy for low income families. And I don't know how you would determine who would [be eligible]. I don't think that's your question, just there is a need. (Gladys, 52)

The homemaker service they have now, is only for low income. It should be extended to anyone and everyone who needs that money. (Dori, 60)

What is unclear from an analysis of the language used in claimsmaking is whether participants understood these claims for “assistance” as *claims for social rights*. Is the absence of explicit references to “rights” in other words, merely a matter of semantics, or is it a more fundamental reflection of how participants conceptualized what “counts” as a right or entitlement in the context of long-term care? Answering this requires an analysis not just of the grievance claims themselves but of the rights consciousness of potential grievants.

#### *E. The Relationship Between Injustice Framing and Rights Consciousness*

An analysis of the rights consciousness of caregivers in this study finds a striking correspondence between the interpretative frameworks used by respondents to understand their caregiving circumstances and the meanings they ascribed to the concept of rights. Those who relied primarily on *legitimizing* frames tended to have great difficulty applying the concept of rights to the context of long-term care, offering narrow and ambiguous interpretations of what

rights “mean” with respect to relationships of care. By contrast, those who relied on *oppositional* frames for understanding their caregiving dilemmas understood the concept of “rights” more broadly to include aspects of care provision. But as the following discussion elaborates, these understandings of rights directly reflected—and were constrained by—the *sources* of their oppositional frames in grievance construction.

Caregivers in this study generally articulated four understandings of “rights” in the context of long-term care, listed in Table 4 below.

TABLE 4: DISTRIBUTION OF RIGHTS INTERPRETATIONS AMONG GRIEVANTS AND NONGRIEVANTS IN INTERVIEW SAMPLE (N=64)

Interpretation of “Rights” in the Context of Long-Term Care	Grievants	Non-Grievants	Total Interview Sample
Confused Understanding	2 (6%)	14 (47%)	16 (25%)
Legal Rights	2 (6%)	5 (17%)	7 (11%)
Moral Rights to Give Care	3 (9%)	4 (13%)	7 (11%)
Social Rights	27 (79%)	7 (23%)	34 (53%)

First, some understood “rights” to be limited only to certain kinds of civil and political rights. These caregivers—one out of four interview participants—could not understand how to extend the rights frame in a meaningful way to the context of care provision. This was most clearly seen in responses to the targeted rights question,<sup>48</sup> where the most common response was one of befuddled incomprehension. Unlike those caregivers who required some clarification of the question (e.g., “Do you mean paid caregivers or unpaid caregivers?”), these respondents fundamentally did not understand how to apply the concept of rights to their circumstances. The following responses are typical in this regard:

My goodness! [laughs] What rights do family caregivers have? My god. You got me. What *rights*? (Bridget, 65)

<sup>48</sup> “If someone from another country were to ask you what rights family caregivers like yourself have in the United States, how would you answer that question?”

What rights? I don't know about rights. You just, to me you just do what you have to do. (Alex, 70)

For these caregivers, the ideology of care provision as a family responsibility was so hegemonic, they had never even considered the possibility of state obligations for care as a matter of *right*. Many of these individuals instead associated “rights” with “rights talk” in political discourse (cf., Glendon 1991). Their discomfort with the appropriation of the term in the context of care provision was evident in the following responses:

I never thought of a right for a caregiver. And yet I hear it all the time. Rights for this and rights for that. I wasn't in that generation. I'm way back where you fended for yourself, I think. ... Never thought of it that way. ... Oh shoot. What right do you have to want a right? [laughs] What kind of answer is that? I can't answer it! (Belle, 81)

Rights. It's a hard one, rights. ... I'm not a fighter. ... I'm not an arguer. If you and I had a disagreement, we would sit down and talk about it. ... So when people have to say “rights” that's probably because it's just not my personality style, but I have a hard time relating to it. (Elizabeth, 44)

A second interpretation of “rights,” articulated by 7 interview respondents (11%), was that of *established legal rights* associated with power of attorney, conservatorships, and decisionmaking in the end stages of the care receiver's life. “[O]nce you get the legal controls,” observed one typical respondent, “like the durable power of attorney for financial and medical affairs, I would think that you have a lot of rights.” In a similar vein, some talked about their “rights” in cases of elder abuse. Concerns about liability for the actions of patients with Alzheimer's was a recurrent theme among participants, many of whom sought legal advice to ensure that they knew their rights in the event they had problems with Adult Protective Services or the police.

Seven caregivers (11%) understood rights more ambiguously to mean a “right to give care.” Unlike the second group of respondents who made reference to specific legal rights available to them through, for example, power of attorney, these caregivers referenced a *moral* right to advocate on behalf of their care receivers:

I can decide what I want to happen to [my husband]. ... They can't come and tell me what to do with him! I can decide. My family and I can decide. So I think I have every right to do whatever I want. ... I don't think no one can come and tell us anything. I think we have that right here. (Gabriela, 69)

I would say that you have the right to get optimum help for the person that you're caring for. You have that right. It's a right. (Conseulo, 55)

Caregivers also referenced the “right to give care” to *themselves*, echoing a common theme among social workers and support group facilitators about the importance of maintaining one's own emotional and physical health while providing long-term care.<sup>49</sup> Betty's response in this regard is typical: “What rights I have as a caregiver? ... Just for myself, that is for me to take better care of myself and to lead a balanced life. ... That's so important because if [I] go down the tubes so does my husband.”

Finally, over half of the caregivers in the interview sample (34 participants) understood “rights” to mean social rights, state-funded benefits and services such as financial support for caregivers, subsidized day care, respite care, etc. Whereas caregivers who understood rights to refer to formal or informal decisionmaking powers in care provision tended to understand themselves as having “as many rights as any other person has rights,” caregivers who understood rights to include social provision observed that caregivers in the United States have *no* rights:<sup>50</sup>

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<sup>49</sup> The emphasis on “self care” in social services is elaborated in Chapter 2 of this dissertation.

<sup>50</sup> Remarkably, only two caregivers in this study referenced entitlements under the new California paid family leave act, which had gone into effect just months before the observation period for this study began.

I don't see...that they do anything, I mean as far as the government is concerned, as far as helping a caregiver. (Gina, 61)

I would say I don't know that they have any rights. I don't think caregivers are really addressed in our system. (Mary, 56)

When given a follow-up probe—"What rights do you think caregivers *ought* to have in the United States?"—grievants often gave answers consistent with the "claims" they had articulated for their caregiving dilemmas—they wanted financial support, subsidized day care, respite care, social workers, etc.

The distribution of these four understandings of rights corresponded to participants' use of legitimating versus oppositional frames. Three-quarters of those caregivers who relied exclusively on a *legitimizing* frame in talking about their care situations (23 participants) interpreted "rights" narrowly, as legal or moral rights to give care—or they didn't understand how to connect rights to care at all. By contrast, more than three-quarters of the caregivers who relied on an *injustice* frame during the course of the study (27 participants) described "rights" more expansively, to include rights to government entitlements.

The gender composition of these groups is worth noting. A nonstatistical comparison finds that while men and women were equally likely to articulate an injustice framing in this study, they had somewhat gendered understandings of what rights "mean" in the context of long-term care. For example, all of the caregivers who interpreted rights to mean a right to care or advocate on behalf of their care receiver were women, and women were twice as likely to be so confused by the targeted rights question that they could not provide a coherent answer. While there were only modest differences in the proportion of male and female caregivers who understood rights to include social rights, the deviant cases are noticeable: all of the 7 caregivers who articulated an injustice framing but who held more limited understandings of rights were

women; whereas 3 of the 7 caregivers who relied on a legitimating frame, but who understood rights to include rights to social provision, were men. Again the sample sizes here are both very small and nonrandom—hence a test of statistical significance is impossible—but these findings would be consistent with longstanding cultural understandings of men as independent, rights-bearing citizens, and women as dependent, and nonrights-bearing caregivers (see Fraser 1997).

Finally, while respondents who relied on an oppositional framework for interpreting their unmet caregiving needs demonstrated a strong tendency to view care provision as a responsibility of government, the framework many of these caregivers used for invoking government intervention directly reflected the *source* of their oppositional frames: the means-tested benefits available under Medi-Cal. Unlike social insurance “entitlement” programs such as Social Security or Medicare, Medi-Cal is a *public assistance* program designed to provide health benefits only to those unable to provide for their own health care needs. Many of those respondents who relied on Medi-Cal benefits as a source for oppositional interpretations of care provision, spoke about “rights” not as a state entitlement, as in the case of social insurance programs, but as *a means of obtaining specific services for those who needed them*.<sup>51</sup> Their emphasis, in other words, was less about community responsibility or social obligations, than it was about the *satisfaction of needs*. From this perspective, those who receive Medi-Cal benefits were understood to have “rights” in the same way that the wealthy do: in both cases, beneficiaries have the means to satisfy the needs of their care receivers. Only those caught in the middle have no “rights”:

[I]f you’re very poor, or very rich, you don’t have to worry, but if you’re middle class, you have to worry a lot. Because...the rights that are there [for them] are not there [for us] and you could go broke. (Reba, 78)

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<sup>51</sup> A more in-depth analysis of the ideological justifications given by nonpoor caregivers for seeking Medicaid benefits can be found in Chapter 4.

[If] you're very poor, or you're very rich, you get whatever you want. But the middle man doesn't get anything. So you better not get sick. I advise you to come to this country and be well, because you're not going to get help. (Susanna, 59)

Dora, a former caregiver for her mother, had a very sophisticated understanding of the structural conditions that make caregiving so difficult for so many in this country. She was an outspoken advocate for expanded government entitlements for caregivers and had testified in legislative hearings about caregiving in Sacramento. But like others, she equated "rights" in the context of long-term care with the ability to meet caregiving needs; as such, one's rights were limited by access to resources:

You could take care of your loved one, if you had a million dollars set aside for everybody. ... You could have someone come in at 7 o'clock in the morning, [who] gets the person up, who helps them with their personal grooming, who makes up the bed, who cleans up the bed if it's soiled or takes their soiled clothes out and washes, all of that can be paid for if you have the resources....So if you have the resources you can manage your situation very comfortably. So the rights to that are all predicated upon resources. And most people don't have, you know, limitless resources.

Thus while the rights consciousness of grievants reflected an expanded understanding of the government's responsibility for helping care providers, that understanding was itself shaped by the oppositional frame with which the grievances were formulated. Caregivers' claims for state intervention *did* challenge hegemonic norms about family care provision, but they did so within a means-testing framework which posits a limited government role in health and economic welfare.

These findings are consistent with our understanding of how new rights claims are formulated: to be *resonant*, new rights claims must be integrated with previous meanings of rights and/or other normative languages (Polletta 2000; Primus 1999). To be resonant in this case, then, new rights claims would have to be integrated with deeply-entrenched beliefs about

family responsibility for care provision. By this standard, it makes sense that a needs-based discourse was a more meaningful framework for articulating injustice claims than social insurance discourse: grievants in this case believed that families should be primarily responsible for care provision, and expected the government to provide “help” or “assistance” only when families needed it. By contrast, a social insurance model of state intervention, which positions care provision as primarily a *state* responsibility, symbolically suggested to many caregivers that the state would be “taking over” long-term care obligations that more properly belonged to the family. Ruth, a caregiver for both her parents, captures this concern that relying on the state for more than need-based benefits might be perceived as abandoning one’s responsibilities to family:

I have mixed feelings about it. ... I’m definitely believing in home support services, definitely believe people need to have assistance with respite care and caregiving. I definitely believe in those things. ... [M]y political stance in general is that I much rather for ...government to take care of those kinds of stuff than bombs and wars and all the stupid things they do. So I’m much more for the government helping people out with these things. But I also can’t say that I totally believe that I don’t have any responsibility in this. So ... I think what I would like for people to do, for government to do, is to help people when they need help.

In arguing that the social insurance framework for social provision was less resonant to participants than a need-based framework, I do not mean to suggest that caregivers were *opposed* to Medicare benefits for long-term care. Few caregivers in this study ever demonstrated outright opposition to government assistance. Rather, I argue that caregivers were more likely to articulate injustice claims within a needs-based framework for social provision. Even caregivers who challenged dominant cultural understandings of care provision as exclusively a family responsibility by conceptualizing their circumstances as *unfair* nevertheless retained the hegemonic assumption that care provision is a responsibility of *families first*, insisting that the government should assist families only when all “private” systems fail.

#### IV. CONCLUSION

Virtually all of the caregivers in this study maintained strong normative commitments to the idea that families should bear primary responsibility for long-term care on their own. So hegemonic was this presumption of care as a private responsibility, that the possibility of any alternative interpretation did not occur to most caregivers until or unless they faced some crisis in care. *How* participants evaluated their care crises—whether they saw their struggle to provide care as a source of guilt or embarrassment or anger and moral indignation—depended largely on who they blamed for their unmet care obligations. For most caregivers, the government was not a natural target for blame; few had any specific ideas when they began caregiving about what the government could or ought to do to assist in long-term care provision. The most common source of oppositional interpretations about care provision for these caregivers was the State’s Medi-Cal program: Medi-Cal benefits granted to some members of their community provided caregivers with a concrete, resonant example of what they could reasonably expect from the state with regard to assistance, and these expectations in turn formed the basis of their claims for assistance.

I conclude with two observations about the claims that emerged from these processes of injustice framing. First, despite a weak historical and cultural understanding of social citizenship in contexts of care provision, there do appear to be circumstances in which the newly-emergent care needs of contemporary American families give rise to new meanings and expanded understandings of rights. While a small group of caregivers professed to strong leftist political ideologies that arguably predisposed them to interpret their care dilemmas as injustices and to direct their injustice claims against the state, many caregivers forged their understandings about “what counts” as a right through their experiences seeking solutions to their care dilemmas.

Having begun the caregiving experience with few, if any, expectations of the state, caregivers who adopted injustice frames for their care dilemmas tended to understand “rights” to include a right to state assistance for care provision. This view of rights departs not only from the normative tendency in the United States to conceptualize citizens’ relationship to the state mainly in terms of civil and political rights, but also from understandings of social rights as attaching to the independent, autonomous market participant: here claims for state intervention explicitly involved relationships of care and dependency. They represent what Linda Gordon (1994, p. 167) has called “the bringing into public of a private logic,” calling for public/state solutions to ameliorate problems long considered the private responsibility of families.

Second, while new understandings of social rights can emerge in contexts formerly considered the prerogative of the private family, those understandings are *constrained* by the oppositional frames in which grievances are forged. If, as Polletta argues (2000), “radical but resonant” meanings of rights can be constructed by integrating rights discourse with other normative languages, here we see that integration may come at some cost to the range of meanings that individuals ascribe to the concept of “rights.” In this case, the primary source of oppositional frames for caregivers was a public assistance program in which the government plays only a minimal role in helping individuals who cannot satisfy their own caregiving needs. As a result, the rights consciousness of grievants in this case reflected a *needs*-based, rather than *entitlement*-based conception of the responsibilities of the state in care provision. This needs-based conception of state responsibility served as a resonant oppositional framework for those caregivers who believed simultaneously in the primacy of family responsibility for care provision and in the responsibility of the state to ensure that families can meet that responsibility.

But I argue that the needs-based framework may also *constrain* caregivers' capacity to articulate their grievances as political demands. It was notable that those individuals who articulated claims for state intervention rarely relied on the discourse of rights or entitlements to do so. Instead, they emphasized care *needs* and *services* and the *help* or *assistance* that the state could provide in meeting the care needs of their family members. The needs-based claims in this case connoted less a sense of *entitlement* than a *failure* in some capacity to meet the expectations of family obligation and care provision. In this sense, the needs-based claims that emerged from processes of grievance construction represented a *passive* form of claimsmaking. There is, as others have argued before (Scheingold 1974; Waldron 1996; Williams 1987), a critical qualitative difference between *asking for help* and *demanding one's rights*. Claims of rights demand a degree of attention and dignity in American political discourse that claims of needs, long associated with "charity," rarely garner. "The experience of our century," Jeremy Waldron (1996, p. 94) once wryly observed, "has not shown that officials are galvanized to action by the discovery that somebody needs something, even to survive." Because needs-based claims are based more on the perceived failure of individual family caregivers to take care of their own than on the failure of the state to take care of its own, needs-based claims are always one half-step away from the demobilizing possibilities of shame, guilt, and embarrassment.

I began this chapter by posing the following dilemma: How can political demand for new social rights claims ever be constructed in a context in which potential grievants have no resonant social rights discourse with which to formulate oppositional claims? The data from this case suggest that individuals *can* construct grievances in the absence of a resonant social rights discourse, and that these grievances can have important consequences for how individuals understand the meaning of "rights" in the context of health and economic security. But the

needs-based claims that emerge from these processes of grievance construction are only as ambitious as their source. If in this case caregivers had recourse to a resonant social rights frame, their claims might have challenged us to develop new ways of conceptualizing citizenship, community, and social responsibilities of care. In the absence of a resonant social rights discourse, caregivers' claims challenge us to do something substantially less: to ensure only that our most basic needs are met by family, with help when absolutely necessary from the state.

## CHAPTER 4

### IDEOLOGICAL JUSTIFICATIONS FOR STATE INTERVENTION

*Most debates over welfare state policy have been framed in terms of [a] contract-versus charity opposition. Invidious distinctions are drawn, for example, between “contributory” programs and “noncontributory” ones, between social insurance ... where beneficiaries have a right to what they receive, since they merely “get back what they put in,” and public assistance, where they have no such right, since they are thought to “get something for nothing.” These extremes, perversely, appear to exhaust all social possibilities.*

—Nancy Fraser and Linda Gordon (1992, p. 47)

In Chapter 3, I argued that in formulating claims for state intervention, Medicaid was a more resonant source of oppositional interpretations of care provision than Medicare, in part because it integrated families’ need for state assistance with beliefs in the primacy of family responsibility for care. In this chapter, I more closely analyze the discourse used by family caregivers seeking Medicaid long-term care benefits to illuminate how caregivers understood their relationship to the state and the state’s role in protecting the economic and health security of its citizens. On the spectrum of evolving political consciousness, a more developed oppositional consciousness would incorporate not just a sense of collective identity and injustice, but an *ideology*, an internally coherent set of ideas and beliefs that links understandings of how the world works with values and normative principles relevant to promoting social change (see Oliver and Johnston 2000).

That nonpoor caregivers in this study were drawing on the discourse of a means-tested public benefits program normally stigmatized as “welfare” would seem to contradict nearly a century of ideological distinctions between contributory social insurance programs for the middle class, and public assistance programs for the undeserving poor. In fact, virtually all of the mostly middle-class caregivers who sought financial assistance for supportive services in this

study looked into eligibility for Medicaid, in many cases arranging their financial affairs so that their care receivers qualified for benefits despite the program's stringent eligibility standards. That middle-class caregivers were actively pursuing public assistance benefits intended for the poor, suggests that the realities of contemporary care provision may not neatly correspond to political and cultural demarcations between different forms of public provision or the ideologies that justify them. Analyzing caregivers' own justifications for seeking Medicaid benefits, I argue that caregivers' views on the state's role in long-term care provision in fact correspond with neither the traditional social insurance model of welfare state provision nor the residualist or public assistance model; instead, caregivers *blurred* ideological distinctions between "entitlements" and "safety nets," insisting on an expanded role for state assistance for the middle class, but falling short of endorsing principles of universal contributory insurance.

In Part I below, I provide some historical context for the longstanding distinction between social insurance and "welfare" models of welfare state intervention, as well as political context for how contemporary political actors in the United States situate the problem of long-term care costs within these competing ideological frameworks. In Part II, I briefly review the coding strategies used to analyze caregivers' values and principles regarding state provision in this case. In Part III, I more closely analyze the phenomenon of means-testing and the middle class, seeking to understand how middle-income caregivers view Medicaid public assistance and how they justify their claims for state intervention with reference to normative principles and beliefs about the state's role in social welfare provision.

*I. THE POLITICS OF PUBLIC WELFARE STATE PROVISION FOR LONG-TERM CARE*

To understand the role of the distinction between contributory social insurance programs and noncontributory “welfare” programs in shaping contemporary American welfare state politics it is necessary to consider its roots in the 1935 passage of the Social Security Act. Prior to the New Deal legislation, virtually all state assistance programs were means-tested programs. The architects of Social Security deliberately used the concept of “contributory insurance” as a way to legitimate old-age and unemployment insurance at a time when the public was deeply suspicious of an expanded role for the federal government (Hacker 2002; Skocpol 1995). Advocates characterized the new Social Security program not as a government tax on workers and employers to pay benefits to retired people (which it effectively was), but as “a huge set of public piggy banks” (Skocpol 1995, p. 162) in which prospective “beneficiaries” stored their individual contributions for their own future retirements. The “contributory” rhetoric gave the impression that the government was establishing a “contract” between itself and citizens (or more accurately, workers), and that old age benefits were “earned entitlements” or rights which individual citizens could claim in the courts if necessary (Fraser and Gordon 1992; Gordon 1994).<sup>52</sup> At the same time that Social Security advocates promoted the rhetoric of social insurance, federal administrators deliberately maintained a sharp distinction between public assistance and social insurance, staving off political attempts to substitute means-tested old-age pensions for contributory social insurance by keeping public assistance benefits stingy and difficult and demeaning to obtain (Katz 1996; Skocpol 1995).

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<sup>52</sup> After Social Security's passage, Roosevelt famously explained to a critic of the Act's payroll contributions that the “taxes were never a problem of economics. They are politics all the way through. We put those payroll contributions there so as to give the contributors a legal, moral, and political right to collect their pensions and their unemployment benefits. With those taxes in there, no damn politician can ever scrap my Social Security program” (Hacker 2002, p. 106).

The concept of contributory social insurance, of course, was always a legal fiction. *All* welfare state programs are in fact financed through “contributions,” whether through tax revenues or wages deductions (Fraser and Gordon 1992). Social “insurance” programs do not actually comport with actuarial principles, nor do benefits actually reflect financial contributions.<sup>53</sup> But if the discourse about contributory insurance programs and noncontributory public assistance programs did not accurately represent the differences in the programs, it nevertheless proved a powerful influence on future institutions. Not only were future programs—including Medicare and Medicaid—designed within the same two-tier welfare state framework established in 1935, but more than 70 years later, policymakers and the American public continue to view social insurance beneficiaries as “deserving” citizens who have “paid into the system” over the course of their working lives, and “welfare” recipients as undeserving or barely-deserving poor people trying to get government “handouts” for free.

Today, the distinction between the two tiers of the welfare state has come to embody two fundamentally different ideological approaches to state responsibility for the health and economic security of American citizens (Fraser 1989b). The social insurance model embodies the ideal that the government, rather than the private (family or market) sector, should be responsible for maintaining health and economic security (Marmor, Mashaw and Harvey 1990). By contrast, the residualist or need-based approach represents the view that the government’s role is that of a “safety net,” granting temporary, subsistence-level relief only to those who are unable to provide for their own needs. The distinction between the two ideological approaches represents a key schism in contemporary welfare state politics between political actors

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<sup>53</sup> Taxation and benefit schedules are tied to income, but Social Security beneficiaries are often entitled to pensions exceeding those which, in a strict actuarial sense, they have “earned” through contributions. In this sense, American social insurance is mildly redistributive across groups of workers.

maneuvering to restructure and privatize, defend and expand today's public social welfare programs (see, e.g., Hacker 2002; Skocpol 1991; Somers and Block 2005; Stevens 1988; Wilson 1987). But I suggest in this chapter that when it comes to the "crisis in care"—the increased demand for care of dependent family members in the face of a shrinking supply of private care within the family—neither the ideology of social protectionism nor that of residualism fully accords with the lived experiences of contemporary American families.

This is perhaps nowhere more evident than in the surging numbers of the middle class seeking to join the ranks of Medicaid beneficiaries. Because long-term care provision has historically been understood to be the responsibility of the family, American systems of market and state social provision have not yet evolved to match the realities of care provision faced by many contemporary American families. Few families can afford to pay for market-based long-term care for sustained periods of time. The average annual cost of a private room in a nursing home in the United States is just over \$74,000, while the hourly cost of home health care is on average \$19 per hour.<sup>54</sup> Unlike the market for acute care, private insurance tools for financing chronic care are relatively undeveloped, and are an affordable option only for a very few Americans (Meyer 2005).<sup>55</sup> Policies must be purchased prior to the onset of illness and usually at a younger age; premiums are usually very high relative to other forms of insurance, and prohibitive once people reach the age of retirement.<sup>56</sup> Indeed, even long-term insurance

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<sup>54</sup> Statistics are from the 2005 Metlife Mature Market Institute.

<sup>55</sup> Currently, only 5-7% of the current elderly currently have any form of long-term insurance (Meyer 2005).

<sup>56</sup> A 1997 *Consumer Reports* article suggests that only 10-20 percent of the elderly can afford long-term care insurance, noting that two "adequate" policies purchased at age 65 cost \$3,500 a year, or 13 percent of the median annual income of elderly married couples ("How Will You Pay for Your Old Age? A Special Report on Long-Term Care Insurance" 1997)

companies concede that their policies may well be an inappropriate solution for most working- and middle-class Americans (Burwell 1991).<sup>57</sup>

Families do not fare much better in the public sector. Medicare, which has historically provided for the acute health care needs of Americans over the age of 65, covers only 100 days of care in a nursing facility for those recently discharged from a hospital and who need skilled nursing care or rehabilitative therapy. Medicare also provides some home health benefits for those with chronic or disabling conditions, but these too are limited to skilled nursing care and are intended as short-term coverage for post-acute care following a beneficiary's hospitalization. For those who need assistance with personal care (bathing, dressing, feeding, etc.), adult day care (particularly to assist family caregivers who work), respite care, or extended nursing home stays, Medicare provides no coverage.

By contrast, the Medicaid program, originally established to ensure that low-income families had access to acute medical care, has evolved into one of this country's most important public sources of long-term care assistance. Although less than 10% of Medicaid beneficiaries use long-term care services, long-term care accounts for approximately one-third of total Medicaid spending (O'Brien and Elias 2004). Given the average annual costs of nursing home care, the financial consequences of an extended stay can be devastating for families. In 2000, approximately 40% of nursing home residents relied on Medicaid as their primary source of payment at admission (either because they were already poor or because they had previously "spent down" their assets due to high medical expenses) (O'Brien and Elias 2004). Another 20% entered nursing homes and subsequently depleted all of their life savings until they were

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<sup>57</sup> One insurance industry estimate suggests that a single person ought to have at least \$40,000 in liquid assets to consider purchasing long-term care insurance (Polniaszek 1997).

technically impoverished—at which point they qualified for Medicaid coverage (O'Brien and Elias 2004).

Because Medicaid is the only public program to offer assistance with the costs of long-term care, the means-tested program has been used more and more in recent decades by middle-class families, and it is this fact that has turned the program into a flashpoint for political contention. Concerns among fiscal conservatives that Medicaid is evolving into a “middle-class entitlement” have provoked a storm of criticism from the right. Critics point to an “industry” of elder law attorneys (“Medicaid--A Middle Class Entitlement?” 1996) whose mission is to advise clients with sizeable assets about how to preserve their estates and still obtain Medicaid to pay for nursing homes (Beck and Hager 1992; Burwell 1991; Burwell and Crown 1996; Kosterlitz 1991). Commentators charge that not only are the middle- and upper-income elderly who seek Medicaid drawing finite resources away from other Medicaid beneficiaries (mainly poor children and their families), but they are fostering a middle class “sense of entitlement” that creates a significant barrier to the expansion of private long-term care insurance or other more rational financing systems for long-term care (Moses 1993; Moses 1996). “[W]hy should someone buy private long-term care insurance,” observes a report on Medicaid estate planning paid for by the Health Insurance Association of America, “if, for less money, they can hire an attorney, shelter their assets, and get ‘nursing home insurance’ through Medicaid?” (Burwell 1991, p. 5).<sup>58</sup> Such criticism has been accompanied by a number of legislative initiatives designed to make it more difficult for the nonpoor to use Medicaid as a safety net, including restrictions on asset transfers, penalties for attempts to illegally shift assets for the purpose of gaining Medicaid eligibility, and controversial estate recovery programs to recoup assets after the death of middle class

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<sup>58</sup> For a discussion on the empirical evidence (or absence of evidence) behind many of these claims, see O'Brien (2005).

homeowners who receive Medicaid benefits (Grogan and Patashnik 2003b).<sup>59</sup> Concerns about the effects of Medicaid trends on the long-term care insurance industry have also sparked a wave of proposals to offer more liberal tax-incentives to make long-term care insurance more affordable for the middle class.<sup>60</sup>

If conservative Republicans have been concerned about the development of a “middle-class entitlement” to Medicaid, Democrats have been eager to *promote* this characterization. Grogan and Patashnik (2003a; 2003b) have documented how, during the clash with Gingrich-Dole Republicans over the 1995-96 budget, President Clinton went to great lengths to define Medicaid as a core social welfare entitlement, as valuable to mainstream families as Medicare, educational and environmental programs (Grogan and Patashnik 2003b, p. 60). No president in the history of the program had ever referred to Medicaid in such terms.<sup>61</sup> The Democratic Party

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<sup>59</sup> Although it should be noted that at the same time these reforms attempted to discourage middle-income people from relying on Medicaid, Congress also passed legislation to protect middle class spouses against so called “spousal impoverishment.” Congress adopted a provision in 1988 that significantly raised the amount of income a community spouse could keep if their loved one “spent down” their assets and income to obtain nursing home coverage under Medicaid. This was interpreted as a concession to the fact that Medicaid was widely used by the middle class to pay for nursing home care (Burwell and Crown 1996; Grogan and Patashnik 2003b).

<sup>60</sup> Taxpayers can now deduct premium expenses for qualified long-term care insurance plans from their federal taxable income, but only if their total medical expenses are greater than 7.5 percent of their adjusted gross income. In 2004, President Bush proposed extending the tax deduction to all policyholders, not just those whose medical expenses exceed 7.5 percent. A number of states, in conjunction with the Robert Wood Johnson Foundation, have implemented trial programs that would reduce Medicaid eligibility criteria for those with private long-term care insurance. In California, Connecticut, Indiana, and New York, policyholders can qualify for Medicaid while retaining more of their assets, provided that they first exhaust their private insurance benefits (Johnson and Uccello 2005; Kosterlitz 1991).

<sup>61</sup> President Clinton’s radio address on September 30, 1995 captures this historic rhetorical shift: “Medicaid’s the way our country helps families pay for nursing homes, home care or other long-term care for elderly or disabled persons. Some people would have you think that Medicaid just helps poor children. Well, it does do that, and that is very important. ... But the truth is, two-thirds of Medicaid goes to help to pay for nursing homes and other care for senior citizens and the disabled. Nearly seven of every 10 nursing home residents gets some help from Medicaid. And no wonder—for nursing homes cost an average of \$38,000 a year, and not many of our families can afford that.” Quoted in Grogan and Patashnik (2003b, p. 60).

has also adopted similar characterizations of Medicaid in its political platform (Grogan and Patashnik 2003a; Grogan and Patashnik 2003b).<sup>62</sup>

The tug of war over Medicaid eligibility for the middle class thus reflects a larger ideological debate in social welfare politics over the state's role in assisting families with contemporary problems of care provision: residualists seek to minimize the state's role in safeguarding American economic and health security, and social protectionists seek to defend—and perhaps expand—social insurance entitlements. In what follows, I consider the debate about the state's appropriate role in assisting families with long-term care provision from the perspective of those directly affected by caregiving dilemmas. I examine how individuals seeking state assistance for the costs of purchasing long-term care connect their care dilemmas to normative principles about the state's role in social welfare provision. Faced with deeply-held beliefs about family responsibilities for care on the one hand, and on the other hand confronted with significant care needs that cannot be met through private sector solutions alone, where do caregivers position their claims for state assistance within the two-tier welfare state ideological framework?

In the following section, I outline the specific coding strategies used to answer these questions. My analysis of the ideology of caregivers with developing oppositional consciousness then takes place in three parts. I begin where caregivers begin their search for solutions to caregiving dilemmas: in the private sector. Here I consider the range of alternatives caregivers consider in trying to purchase market-based supportive services, finding that families go to great

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<sup>62</sup> Grogan and Patashnik also note that this strategic attempt on the part of Democrats to recast Medicaid as a mainstream entitlement was not lost on conservatives. The Concord Coalition warned its conservative membership in 1996: “The White House insists on a Medicaid entitlement precisely because it wants to recast Medicaid as a middle class property right perhaps as a prelude to another universal health-care plan, or at least as a popular vote-getter” (Grogan and Patashnik 2003b, p. 61).

lengths to keep the costs of care provision within the family before turning to the state for help. I then analyze the turn to Medicaid, examining how the mostly middle-class caregivers in this study viewed these public assistance benefits and what strategies they used to try to obtain eligibility for the program, despite its strict means-test. Finally, I analyze the discourse caregivers used to justify their claims for state assistance, seeking to identify how caregivers understood their relationship to the state, and the state's responsibilities for assisting families with the costs of market-based care.

## *II. METHODOLOGY*

Where most public opinion research on the welfare state asks respondents to consider issues of social welfare in the abstract, most often at times and in settings where respondents are not actually seeking social welfare benefits (see, e.g., Cook and Barrett 1992), I instead examine the lived experiences of individuals as they seek solutions from the state to problems in their everyday lives (cf., Soss 2002). The distinction is an important one for analyses of the construction of political consciousness, for here we are interested not in participants' attitudes and beliefs about state provision as fixed attributes, but in the contexts that shape those attitudes and beliefs. My aim in this chapter, then, is to examine what the experience of seeking and justifying solutions for the economic dilemmas of care provision tells us about the values and normative principles caregivers hold about the respective roles of family, market, and state in long-term care provision.

Data from support group observations, taped focus group conversations and interviews were analyzed to assess how respondents sought out solutions to caregiving dilemmas that specifically involve the need for market-based supportive services. I coded all references to

needing or using paid supportive services (including in-home care, housekeeping services, meals on wheels, respite care, adult day care, and nursing home care). I then examined how family caregivers purchased the additional care, coding all references to *private* family- or market-based solutions to care dilemmas, including (1) nonutilization, or instances in which participants chose to forego market-based care due at least in part to cost; (2) family assistance, or cases in which caregivers obtained hands-on or financial assistance for care from other family members; and (3) long-term care insurance. I also coded all references to *public* solutions to care dilemmas, including references to government subsidies, and Medicare and Medicaid benefits. Note that given the sensitivity around Medicaid eligibility, I was unable to collect systematic data on exactly how many participants sought out and qualified for Medicaid benefits. (Asking about Medicaid “spend down” strategies is similar to asking people to describe their tax evasion strategies, but with the added social stigma of seeking access to a “welfare” program.) Nevertheless, the fact that over half of the caregivers interviewed volunteered information about Medicaid eligibility suggests that the phenomenon of seeking (if not qualifying for) long-term care public assistance among the middle class was widespread.

Finally, I coded field notes and transcripts for indicators of how caregivers viewed their relationship to the state and how they justified their claims for state intervention in care provision. I coded references to citizenship, government responsibility, and references to government spending priorities. I also coded the texts for references to concerns about “big government”—bureaucracy, fraud and abuse, fears of Socialism. Finally, I analyzed the use of key terms that connote particular ideological positions or normative claims in the contemporary context (cf., Fraser and Gordon 1992; Fraser and Gordon 1994). These included references to “deserving” and “undeserving” beneficiaries and “entitlements” and “handouts.” For interview

participants, I also analyzed data on respondents' political ideology (liberal, moderate, conservative, and other) and the party for which they typically vote (Democrats, Republicans, Other). Taken together, data from support group observations, focus groups, and interviews provided a full portrait of how participants perceived—and responded to—the problems associated with the purchase of supportive services, and how they connected those problems to normative principles about the state's role in long-term care provision.

### *III. PRIVATE AND PUBLIC SOLUTIONS TO OBTAINING SUPPORTIVE SERVICES*

The previous chapters have demonstrated that the normative ideology in the United States with respect to care provision has historically been—and continues to be—one of private, family responsibility: participants in this study viewed the family rather than the state as primarily responsible for caring for the elderly and infirm and believed they should do so through their own resources. The contemporary crisis in care, however, has arguably strained this longstanding view by introducing the very real possibility that, given the cost of market-based care, and the duration of chronic diseases such as Alzheimer's, families' resources for care provision may ultimately be insufficient to meet their perceived care needs. In this section, I argue that caregivers' search for solutions to the economic dilemmas arising from the need for market-based care begins in the private sector, and only when private-sector options fail to resolve their care crises, do individuals turn to the state for help. These claims for state assistance, however, do not fall neatly within traditional paradigms for justifying welfare state provision, but instead appear to straddle both residualist and social insurance traditions in an effort, I argue, to reconcile caregivers' normative commitments to family care with the contemporary realities of care provision.

A. *Private Sector Solutions to Purchasing Supportive Services*

For many caregivers, it is an emotionally difficult step to acknowledge that one needs to hire assistance in providing care to a family member (cf., Abel 1991; Brody 2004; Ungerson 1987). The step is made all the more difficult by the fact that for most middle-income Americans the cost of purchasing care is quite prohibitive. At the start of this study, Leda was gathering information on hiring a caregiver to provide in-home assistance for her husband, who has Alzheimer's disease. She spoke to someone she knew whose husband also had dementia and who had full-time care in the house, and she then reported back to her support group:

They're middle class people. I don't think I heard incorrectly, I thought she said that she paid \$3,500 a week! Now maybe she meant a month. ... [W]hat do people do who cannot afford this kind of thing? How do they deal with this? I mean...the financial issue, what do people do?

Henry was caring for his wife, who was diagnosed with Alzheimer's disease two years ago. At 79 and in poor health, Henry conceded that he could not adequately care for his wife himself, but refused to place her in a skilled nursing facility. Instead, he looked into hiring a live-in caregiver.

When I found out what the cost was going to be, I'm telling you ... I did a lot of praying. Because [my wife] and I, we're just average Americans I guess. We're not rich. We live on Social Security and a small pension. But I mean, we were getting by alright. But we didn't have no \$45,000 surplus dollars! Most people don't!

In general, caregivers confronting the high costs of market-based supportive services relied on three strategies for resolving their caregiving dilemmas: (1) foregoing supportive services and relying exclusively on unpaid family care; (2) paying for supportive services out of pocket and/or pooling family resources; and (3) using long-term care insurance.<sup>63</sup> All of these

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<sup>63</sup> These strategies are not mutually exclusive. Caregivers could initially forego services and eventually resort to purchasing them when their circumstances worsened.

strategies reflected a normative commitment to keep the costs of care provision within the family.

Faced with the prospect of paying significant out-of-pocket costs for supportive services, many caregivers in this study chose to forego outside assistance altogether or to delay assistance until their situations had worsened considerably. Many of these caregivers had been reluctant to ask for help even before they became aware of the economic costs; once confronted with the costs it was not difficult for them to reconsider their need for outside assistance. Sharon represents this dynamic quite well. Exhausted from the responsibility of caring for her husband all day and repeatedly waking up during the night to assist him to the bathroom, Sharon felt she had reached a physical and emotional breaking point: “You get used to doing it all yourself,” she recounted. “You go inward. This is what I have to do. It’s 24 hours a day, but I can do it. Then you realize you can’t.” Sharon described the sense of duty she felt at the time: “I felt, you know, I was his wife. And I wasn’t working so I should take care of him. ... I felt that was what I should do. But I remember as it began to sink in how much care he was needing, that maybe I should get some kind of help.” Not knowing where to turn, she asked her husband’s physician for information. “[H]e said well, there are places that you could call ... like nurses aides and things like that, but they’re pretty expensive. And I thought well, I could still do it myself. You know, I began to think, well, I don’t know if we can afford all that.”

Another concern for these caregivers was the possibility that the condition of their care receiver could deteriorate significantly in the future, and some chose to forego paying for supportive services in order to preserve their resources in the event they might later need more advanced (and therefore expensive) help (cf., Brody 2004). Still others struck a middle ground

by purchasing *some* assistance, but far less than they would have preferred—fewer hours of in-home assistance, for example, or fewer days at adult day care.

But for many caregivers, forgoing supportive services was not an option, regardless of the cost. Caregivers who worked in the paid labor force, for example, often needed supportive services so that they could leave the house to work. Social workers in this study also observed that by the time many caregivers seek outside assistance, they have already reached their breaking point—unable physically or emotionally to provide an adequate level of care without the assistance of supportive services. Of those caregivers who did hire care assistance, virtually all of them paid for the assistance out of pocket, tapping into their lifetime savings and retirement accounts. Retirees lamented the fact that the money they had saved for retirement or to pass on to their children was now being spent almost exclusively on caregiving. “T]here isn’t much life,” observed one retiree, caring for his wife, “because everything you’ve saved for was going to be used for your old age and happiness and travel and so forth and enjoying your life, and then your life took a quick turn in the other direction.” Adult children providing care for their parents worried about the future consequences of these financial outlays.

[Y]ou find yourself in the position of having to take care of a loved one, you use up all of their resources and a lot of your own resources, and who’s going to take care of you, you know, when you reach that age when you need assistance? Your resources are gone, caring for someone a generation older than you.

When the costs of purchasing supportive services were beyond the individual caregivers’ capacity to pay, it was common for other family members to make financial contributions to alleviate the burden. While many of the elderly caregivers in this study expressed discomfort in burdening their adult children with caregiving responsibilities, most had few alternatives but to accept financial assistance. Family responsibility again played a key role in these negotiations.

Reba was caring for her 80-year-old husband, who was diagnosed with Alzheimer's disease four years ago. Her son and two daughters decided among themselves that they would split the cost of adult day care, as they were concerned for Reba's long-term financial solvency if she attempted to pay the bill on her own. "And at first I didn't want to do it because I didn't want to take it from them," she told me. "I said that's not right. They said well what about all the years you did it for us? So it's really nice of them. And we split it four ways. It's a lot easier."

By relying largely on unpaid family caregiving labor and by paying for supportive services out of pocket or with the assistance of other family members, caregivers in this study demonstrated a strong normative commitment to keeping the costs of long-term care within the family. But for most working- and middle-class caregivers, the cost of purchasing supportive services, particularly for patients who needed intensive, 24-hour care, exceeded their family's ability to pay. Long-term care insurance provided one last private-sector financing option, but issues of availability, affordability, and coverage limitations remained significant obstacles for most caregivers who explored this option. Many older caregivers, hadn't known long-term care insurance existed when it would have been affordable to purchase a policy and when medical exclusions would not have been an issue.<sup>64</sup> For others, the insurance premiums were simply too expensive. Still others had contemplated purchasing long-term care insurance when they were younger, but determined that the odds of needing long-term care assistance did not justify the expense. For people in their 40s and 50s, other financial pressures—raising kids, paying for college, and saving for retirement—competed for scarce resources, and few were thinking about long-term care then at all.

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<sup>64</sup> Private insurers typically offer coverage only to individuals in good health at the time of enrollment. People with a history of heart disease, diabetes, arthritis, hypertension, dementia, or recent hospitalization are routinely screened out. Thus, it was obviously too late for most caregivers to obtain long-term care insurance for their chronically ill family members.

While these caregivers reflected on long-term care insurance as a missed opportunity, some caregivers *did* purchase insurance policies but were reluctant to actually *use* them. Many of these caregivers discovered, long after the policies were purchased, that the policies contain coverage limitations they had not anticipated—restricting coverage to two or three years, for example, or to nursing home care only. Families faced with illnesses of indefinite duration were reluctant to start the clock on these policies for fear that their caregiving needs might be far more significant in the future. The issue of coverage limitations discovered *ex post facto* was a common topic in support groups, where caregivers both voiced their frustration with their policies and issued cautionary warnings to their peers. Reba had just started taking her husband to adult day care at the start of this study’s observational period. She called her insurance company to find out whether it would cover the cost and reported back to the group: “I’ve been paying a lot of money for long-term care, and then I called the person that sold me the care, and they said it’s only good for two years.” The insurance representative told Reba that the company would pay for the day care, but the costs would be subtracted from the total coverage provided under her policy. She relates the conversation she had with the insurance representative:

And I says well that’s terrible! ... So he says but [use the policy anyway]. I says no, I’m not. He said what if you never use it? I says I’ll use it, but I want to use it when I can. ... And he says what you do is you use it up and then you put everything in your name and so when the time comes, he has to go on Medicaid ... . [B]ut I just want to play it as I can. ... [T]he more I use it up, it’s like a big amount they give you and once it’s over, it’s over.

Trenton, caring for his 80-year-old wife, who has Alzheimer’s also acknowledged that he had a long-term care insurance policy, but like Reba, he was worried about actually using it: “I have one that is only for two years. I didn’t realize it. ... It would be a great help now, but if my wife

goes beyond the two years ... I have some cash money and hopefully that would carry me maybe a year or two, but after that maybe my house ....”

These stories cropped up regularly in support group meetings. Caregivers warned each other about the pitfalls of long-term care policies, and social workers and attorneys routinely offered to review policies purchased five, ten, or twenty years previously so that caregivers would know their policy limitations as they assessed their options for financing supportive services. As a result, there was a strong sense among caregivers in the study that the long-term care insurance market is unreliable, and in some cases untrustworthy. Few caregivers knew anyone who was significantly assisted by any form of insurance coverage. Of the nearly 160 caregivers in this study, only 6 reported using long-term care insurance to cover the costs of supportive services.

If the working assumption for most caregivers in this study, then, was that they should do their best to cover the costs of supportive services through private-sector solutions, that assumption was sorely tested once they confronted the costs of purchasing care. Whether they turned to adult day care, in-home assistance or skilled nursing facilities, the cost of purchasing care in most cases substantially drained savings the caregivers had hoped would last their lifetimes or exceeded their capacity to pay altogether. With few, if any, satisfactory financing options available to them in the private-sector, these caregivers looked to the state for assistance.

#### *B. Public-Sector Solutions to Financing Supportive Services*

Virtually all of the caregivers who sought financial assistance for supportive services at some point looked into Medi-Cal, and in some cases specifically arranged their financial affairs to obtain benefits otherwise only available to the very poor. In this section, I describe how these

mostly middle-income caregivers<sup>65</sup> viewed and maneuvered around Medi-Cal eligibility standards.

Like most means-tested state assistance programs in this country, the income and asset eligibility requirements for Medi-Cal are very stringent<sup>66</sup>. While those who qualify for CalWORKS (previously AFDC) or Supplemental Security Income (SSI) are automatically eligible for Medi-Cal, most of the family caregivers in this sample had incomes well above the eligibility requirements for either program. Reaction from middle-class caregivers to the standards for Medi-Cal eligibility was frequently one of open dismay. “I looked into . . . Medi-Cal,” Trenton, a middle-class retiree, told me. “[I]t’s practically *impossible* for a person with adequate means to get into Medicaid. You have to be penniless almost!” For the nonpoor caregivers in this sample, the means test was set so far below their standard of living, they could not comprehend living on what Medi-Cal permitted. Elliott, whose annual income was over \$70,000, reacted to the Medi-Cal eligibility standards in typical fashion: “But Medi-Cal is almost like you’re a homeless person! . . . How can you exist on that little money?” Lynne’s household income was about \$24,000, just above the eligibility cut-off line. In poor health herself, she was trying to provide care for her husband and mother, both of whom had been diagnosed with unspecified dementia. She was unable to afford supportive services, but neither did she meet the eligibility requirements for Medi-Cal: “[W]e’re too rich to qualify for anything!

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<sup>65</sup> Most caregivers who sought financial assistance with supportive services had incomes between \$30,000 and \$70,000.

<sup>66</sup> In California, the “need standard”—or the amount of monthly income that the state determined is necessary for an individual to meet monthly expenses, not including medical bills—is \$600 a month or \$934 a month for an elder/disabled couple. Individuals cannot qualify for state aid unless they have less than \$2,000 in financial assets. Clothing, jewelry and furniture are generally exempt from consideration. Applicants are also permitted to keep a car, as long as they can show that the car is used for medical purposes. Generally, if an individual has an income above the “need standard” and a doctor determines that nursing home care is “medically necessary,” the patient can qualify for Medicaid, but pay a “share of cost” for his or her medical bills each month.

I think their idea of poverty—and I don't know where these people are living, in Central Park?— is something like two people should be fine with \$19,000. That's ridiculous!" The fact that Medi-Cal was a program designed to assist the *poor*, was lost on many of the caregivers who looked into Medi-Cal financing. One middle-class caregiver reacted to his ineligibility in typical fashion: "You have to be almost poverty-stricken, don't you? Yeah. I was amazed."

The stories of family caregivers with significant care needs who could neither afford to pay for supportive services nor qualify for Medi-Cal, painted a vivid portrait of the dilemmas faced by those caught between the failures of the private and public sectors. Just prior to this study, Serena's husband, diagnosed with Alzheimer's, had deteriorated to the point where he needed 24-hour care. His paranoia, tendency to wander, and increasingly combative personality, took a profound toll on 72-year-old Serena's physical and emotional health. Having reached a point where she acknowledged she needed help, she looked into financial assistance: "Everything we tried, we were not eligible for," she told me, shaking her head. "Everything, everything we tried, we were not eligible."

Face to face with a means test designed to screen out all but the very poor, many middle-class families with few other financial alternatives available to them actively sought out ways to arrange their affairs so that their care recipient ultimately qualified for Medi-Cal. This could be accomplished in one of two ways. First, family caregivers could take advantage of Medicaid asset transfer rules to shift assets to family members, reducing their "means" for purposes of the means test, but without losing ultimate command over their resources (Goodin and Le Grand 1986). Federal laws designed to prevent "artificial impoverishment" on the part of the nonpoor disabled elderly impose a penalty period (during which applicants are denied Medicaid eligibility) for those who illegally divest or shelter assets for the purpose of qualifying for

Medicaid. But to enforce these rules, states must prove that someone divested their assets for the *sole purpose* of obtaining Medicaid benefits. Because people can divest their wealth for a variety of reasons, this case can be difficult to make (Burwell 1991).

In fact, many forms of asset transfers are explicitly permitted under Medicaid rules. In particular, special rules—so-called “spousal impoverishment” protections—allow married couples to set aside income and assets for spouses who will remain living in the community after their loved one is institutionalized.<sup>67</sup> Those familiar with Medicaid rules can find a variety of ways to gain entry to Medicaid (Burwell 1991). In this study, a significant number of middle- and upper-income caregivers sought the assistance of elder law attorneys to inquire into this option. Serena, who had been repeatedly denied eligibility for her husband, eventually hurt her back and needed to place her husband in a nursing facility. It was at this point that she sought the assistance of an attorney:

So what she did was put things in my name, so that he could qualify. And she told me how to get my own checking account and the property tax and everything comes in my name. Because . . . in order for us to qualify, we would have to get down to like \$2,000 a piece. And I was trying to do that, but then the taxes, the property taxes here is like \$1800 something and then we have another property, it was \$1600. And at that time we had three and I sold one. Well there's no way that I could keep the bank account under \$4000 and have the taxes when it's time to pay. So she helped, the lawyer helped me do those things.

Daniella and Vincent, both of whom are caregivers for their respective parents, sought an attorney's help when Daniella's mother was first diagnosed with Alzheimer's. The attorney advised them of Medicaid's “lookback rule”: Because Medicaid's asset transfer restrictions apply only to transfers made within the 30-month period preceding the date of an individual's

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<sup>67</sup> For many years, Medicaid rules required couples to spend down almost all of their assets and income before they could be eligible for nursing home aid. This left the individual still living in the community with few resources on which to survive. The “spousal impoverishment” protections enacted by Congress in 1988 significantly increased the amount of income the community spouse can keep.

Medicaid application, it is legally permissible to transfer assets within the family *before* the 30-month clock begins.

We went down there to see [the attorney], and she was telling us some things that we could do, but my mom was like right in the beginning, she had just barely been diagnosed, so I wish we had gone through with it then. Because now, it's like you do it, but you have to wait like a 2-year process for the property . . . . I wish we had done that like right then and there.

Two years after their initial meeting with the attorney, Daniella's mother now requires far more day-to-day assistance and supervision. The family cannot afford to pay for supportive services out of pocket, but because they did not transfer assets at the time they first sought the advice of an attorney, Daniella's mother is now ineligible for Medi-Cal assistance.

While for most caregivers like Serena, Vincent, and Daniella, asset-shifting was the only way to obtain financing for necessary care services, a few caregivers were quite upfront about the fact that the primary reason for shifting assets was to preserve inheritances for their children. Betty, who was caring for her husband, spoke at length in her interview about her concerns about California's asset recovery policy. Federal Medicaid rules permit states to place liens on the houses of individuals who meet the income eligibility requirements for Medicaid; once the beneficiary dies, the state can then file a claim against the beneficiary's estate to reimburse the Medicaid program for payments made during the beneficiary's lifetime.<sup>68</sup> Horrified that the state of California could take her house, Betty told me: "I would take advantage of all the legal loopholes, so that *definitely* would not happen." Karen, who lived in a large house in a wealthy neighborhood in Los Angeles, was similarly quite clear about her motivations:

I'm very interested in protecting assets, I won't deny that. I didn't spend all my life thinking about ways to acquire, to protect, to pass on to my children up to

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<sup>68</sup> The state is prohibited from making claims on estates if there is a surviving spouse or a minor, blind or disabled child living in the home. According to California Advocates for Nursing Home Reform, California's asset recovery program is the most aggressive in the nation.

now to think of passing it on to strangers ... so yeah, I'm definitely interested in asset protection.

While media coverage often gives the impression that such “artificial impoverishment” is a wide-spread phenomenon, empirical evidence suggests that in fact most of the elderly with disabilities have too little wealth to warrant hiring an attorney to arrange an asset transfer.<sup>69</sup> In this study, only a few caregivers talked about shifting assets for the main purpose of preserving inheritances.

A second much more common, way for nonpoor families to gain access to Medi-Cal benefits is to “spend down” their assets until the care receiver is effectively impoverished, at which point he or she qualifies for Medi-Cal coverage.<sup>70</sup> For some caregivers, spending down lifetime savings to care for a spouse or parent was seen as the natural course of things—what else is your money for, if not to take care of your family? Ida Mae, for example, spent the entirety of her parents’ \$1 million estate on in-home care assistance over a ten-year period. At the time that I interviewed her, her mother had just obtained eligibility for Medi-Cal and had been placed in a nursing home. “I knew nothing about Medi-Cal,” Ida Mae told me. “We came from a more than comfortable family, and couldn’t believe it when I had to resort to that. Because my parents just outlived their money. My mom is 90 today.” For these caregivers, “family responsibility” meant relying exclusively on family resources for care provision, *even when it meant exhausting a lifetime of savings*. The following comments are typical in this regard:

If the money takes care of [my parents], then that’s a load off my back. And that to me, is worth more than all the inheritance. (Vincent, 57)

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<sup>69</sup> See O’Brien (2005) for a review of studies on estate planning and Medicaid.

<sup>70</sup> Medicaid has been characterized as insurance where the deductible is your lifetime savings and the copayment is your annual income (Moon and Mulvey 1996).

I hear so many people say well, we're going to find the legal ways to divest the monies that they have because they're not going to just, after working so hard all their lives, just pay these bills. ... But I just think that's not an honest way to live .... (Jill, n/a)

My feeling is that in a situation like this, [my mother-in-law's] got money. And she's got assets. ... [W]hy should you ask the government to put money toward her care when she can do it herself? ... I mean she's got family that's willing to come in here and look after her. And she's got money you know, to take care of it. ... If someone was in [my mother-in-law's] condition and didn't have a family to look out for her and didn't have any money of her own, those are the people that should get the help from the government. (Eddie, 57)

While these caregivers appeared to take the “spend down” advice from attorneys, social workers, and Medi-Cal administrators in stride, other participants in this study talked about “spending down” with considerable resentment. These caregivers saw the advice as *inverting* long-held American values about work, individual responsibility, and upward mobility. Taught to work hard, pay their taxes, and save for their retirement, the spend-down advice asked them to *spend* their lifetime savings to move *down* the mobility ladder to poverty. Karen typifies this sentiment in the following angry commentary:

[I]t's the middle class that's expected to work all its life, pay high taxes, plot and plan to save for their retirement and to pass on some of what they acquired to their children ... they're expected to drain themselves. I mean, lawyers will say to you go, spend down, go on that cruise. Do this, do that. What do they mean? If you had \$100,000, yes you could spend it down, but what if you have a couple of million [dollars]? And that person is going to be in a home for 10 years. That's going to eat up their money. And there seems to be no help for that!

Isadore, who at the time of this study was just acknowledging that he could no longer care for his wife on his own, expressed dismay that the government would want him to just “spend” a lifetime of savings he had earned through hard work and a “little bit of frugality.”

[T]o ask somebody to go into a nursing home and come up with \$50,000 to spend down, you begin to wonder to yourself well was I right in my frugality or should I have bought a brand-new Cadillac every three years like everybody else? And here the government is taking care of them anyway!

In much of the discourse around Medi-Cal eligibility, caregivers like Isadore compared those who had “done right” by working hard, saving, and paying their taxes, with those who had never worked and were getting help from the government anyway. Their references to “deservingness” in the context of the public assistance program were notable, given that the discourse of deservingness is typically used to distinguish *social insurance* from public assistance beneficiaries. In the following section, I more closely analyze what these mostly-middle income caregivers signaled about their views about the means-tested program and the responsibilities of the state when they relied on this distinction between themselves and “undeserving” beneficiaries. How, in other words, did these nonpoor caregivers seeking “welfare” benefits situate their claims within the two-tier welfare state framework?

C. *Ideological Justifications for Middle-Class Medi-Cal “Entitlements”*

The discourse of deservingness and entitlement with respect to state provision used by social insurance proponents at the turn of the century drew on an understanding of a social contract between state and citizens (Fraser and Gordon 1992): in exchange for working hard and paying taxes, citizens could legitimately expect government assistance with certain forms of social welfare provision when they needed it. By importing the rhetoric of deservingness into the context of the means-tested program, nonpoor caregivers in this case similarly appeared to frame Medi-Cal benefits as *earned entitlements* for the middle class. Caregivers’ use of deservingness discourse to argue for expanded benefits for the middle class suggested, in part, a rejection of a purely residualist view of state responsibility for long-term care: the poor were not the only ones struggling to meet the care needs of their families. But, as the following discussion elaborates, their discourse did not in most cases signal broad ideological support for a social insurance

model of state intervention. Caregivers expressed deep reservations about the state's involvement in care provision and generally maintained a preference for the means-testing approach to social provision. The discourse of deservingness, in other words, was used as a kind of bridge between two distinct ideological traditions to social welfare—emphasizing family responsibility for care provision, but envisioning a broader and more generous safety net to assist the middle class with the costs of long-term care.

Mary, a caregiver for both her parents, exemplified the use of “deservingness” discourse in the following commentary to her support group:

I remember a long time ago when I got divorced. And I had two kids and I was working but ... I was like \$2 over the limit! You know, I have worked, my parents have worked, they have put into the system, but all the people that were sitting there didn't speak English, they all qualified because...because. Because of whatever. I think we've neglected to care for our own and chosen to care for the people who ... and I'm not saying they don't have rights. I'm not saying they don't have rights. But we've chosen to take care of them rather than take care of our own. And I think it's wrong. ... I think we the people who live here and have contributed and our ancestors have contributed, you know, our mothers, our fathers, our grandparents, we should have rights just like they do. And just because we've worked hard and made a *minimal* living shouldn't disqualify people from services.

In Los Angeles, where there is a significant immigrant population, constructions of “undeserving” Medi-Cal recipients were frequently laced with anti-immigrant rhetoric. Dora, who suggested in a peer group session that Medicare and Medicaid be merged so that “everybody gets treated the same way,” nevertheless also drew on this distinction between “deserving” and “undeserving” beneficiaries: “[T]here are too many people, especially in California and some of the border states, where we've got people who are benefiting from Medicare and Medi-Cal that don't pay a thing. And our kids were born in the United States,

their parents and grandparents have all paid taxes, they aren't eligible for anything." Gina is a caregiver for her mother, who is now institutionalized:

I hate to say this, but we have people coming from other countries, and taking so many things that we are paying taxes for. Never had a day job in their life, you know, between food stamps, just automatically well here's a check for you. And we're all paying for this. So I think ... if the government can pay for that, then they can certainly help pay for some of the things that we're out there working to put our taxes in for.

Caregivers repeatedly invoked the idea that because they've paid their taxes or "paid into the system," the help they wanted from the state has in some way been *earned*, in the same way they understood Social Security or Medicare to be earned benefits. But here entitlements discourse did not refer to benefits actually granted by any state authority—most caregivers were ineligible for Medi-Cal benefits under the program's strict income test. Instead, caregivers relied on entitlements discourse in an *aspirational* sense, drawing on cultural symbols and constructs of social citizenship to make a case for what kinds of benefits they felt were owed to them (cf., Minow 1987). The following comments are illustrative:

Middle America's the ones that pay in, so we should be entitled [to the benefits].  
(Joe, 57)

I've been paying taxes all my life. [My husband's] been working and paying taxes all his life. I don't mean that we want to freeload, but the thing is, if you haven't got it, I want the people to have it, and I want there to be a place where you're not worried all the time about how you're going to go destitute. (Reba, 77)

[M]ost of us are not poverty. We're almost there, but we're not eligible because of the way the system is written now.... And sometimes I really feel, when I really want to think about it, it's not fair. Because the people who are \$700 and below, don't pay taxes, and probably don't own property, and I could go on with what they don't have. And those of us who do "own property" or ... pay taxes, we're not eligible. So where does our money go? (Jackie, 76)

These statements reflect a contractual understanding of citizens' relationship with the state, typical of the American contractual approach to contributory social insurance: in exchange for

working and paying taxes, caregivers expected something back from the government when they needed it. “I don’t think we’ll have to have another Boston Tea Party,” noted one caregiver, “but [the government’s] got to understand that they just can’t say give me give me give me give me and not let the people know that okay, while I’m taking, I’m giving something back.”

Nonpoor caregivers thus used the discourse of deservingness to justify their seeking access to a means-tested program more typically considered “charity” or “welfare.” On the one hand, this appeared to be a strategy for preserving self respect while making claims for benefits from a public assistance program: nonpoor caregivers were careful to highlight their status as workers, taxpayers, and citizens to distinguish themselves from “undeserving” Medi-Cal beneficiaries. But the rhetoric of deservingness also implied a rejection of a purely residualist approach to state provision for long-term care. Caregivers who needed financial assistance for supportive services drew on the discourse of entitlements and deservingness to signal their belief that the government had a responsibility to protect middle-income Americans from falling into poverty over circumstances beyond their control. As one caregiver put it: “You shouldn’t have to be poverty-stricken to in order to get help. ... [P]eople did not arrive at that place in life ... on their own. It wasn’t anything they did. ... [W]hen they need help like that, they should be able to get it.”

Importantly, this view of the state’s role in social provision was tied more to participants’ subjective care dilemmas than to either political ideology or income. Thus, most caregivers, regardless of whether they identified as liberals or conservatives, Democrats or Republicans, maintained the belief that the costs of care should be borne first and foremost by families. But by the same token, most caregivers, regardless of their political views, believed that the safety net for long-term care provision should include middle-income Americans. That caregivers who

identified as moderates or conservatives were just as likely as liberals to support an increased role for the state in the case of long-term care was somewhat surprising, and in fact these participants often articulated a self-conscious awareness that their position on this issue contradicted other aspects of their political ideology. Leonard, whose wife is institutionalized in one of the most expensive nursing homes in the greater Los Angeles area, typically votes as a Republican and identifies as a political conservative. “There’s no direct help on the government side except for what I get from the Army,” he told me. “Yes, I do feel that there could be some help that way.” Leonard paused for a long moment: “And I really am torn that way because . . . my philosophy is one where we shouldn’t have handouts. Medical handouts. And yet I do feel that there should be some additional assistance for these people who have extraordinary expenses.” Doris, who is caring for both of her elderly parents, also identifies as a political conservative:

I really come from the view that everybody needs to take care of themselves. But I cede to the point where it’s overwhelming, even if you try your best. [Caregiving is] such a big strain on the family that if there was some assistance, it would be a big benefit to the population.

Gladys, who identifies herself as a moderate Republican, recently moved her mother, who suffers from dementia, to Los Angeles from Arkansas. To provide full-time care for her, Gladys closed her child care business.

I had the assumption that family would just take of their loved ones, and to some degree I still agree with that, but where I differ is the financial burden. . . . I read about where some people have had to dip into their savings, into their own retirements to care for their aging loved ones. I don’t feel that that is right. . . . [F]inancially, we’re in a position we have to make some cutbacks, but we can survive on the one income. But there’s families who cannot.

The belief that families shouldn’t have to impoverish themselves to get help from the government was also shared by caregivers of all class backgrounds. Perceptions of economic

“need” were highly subjective and tied to the consumption patterns to which people of different classes were accustomed. Linda, who relied on her brother’s help to pay for adult day care, was an executive at a major corporation in Southern California. In arguing that supportive services should have a sliding scale for families, she worried that by most objective standards she probably wouldn’t qualify for help:

They would look at my income and they would say, you drive a Jaguar, you know? You’re wearing this [expensive suit]. And you make this money. And then I would say, wait! You don’t know! I paid off my son’s education...this is what I have at the end of the day. This is what I have, and believe me...there’s not an extra \$2,000 there, you know? So it’s just...what they think is a lot of money is not a lot of money.

Caregivers with several million dollars in assets feared the costs of paying for a nursing home that cost over \$150,000 a year, while caregivers with much more modest assets feared the costs of nursing homes costing closer to \$40-\$50,000 a year. Thus, regardless of how close participants actually were to “needing” assistance from the state, the subjective stress and worry about being able to satisfy the perceived care needs of their family members was, in effect, a great equalizer: regardless of income, the fear of falling into destitution or failing to provide adequate care for family was a powerful motive for supporting an expanded role for the state.

Caregivers across the political and income spectrums, then, espoused the view that when the costs of long-term care provision exceed the resources of mainstream American families, those families should be entitled to government assistance. But if caregivers’ *recasting* of Medi-Cal as a middle-class entitlement suggested a rejection of a purely residualist view of state responsibility for long-term care, it was not necessarily a broad endorsement of the social

insurance approach to state intervention.<sup>71</sup> As we saw in Chapter 3, caregivers in this study were often uncomfortable with the idea of a social insurance model for care provision, fearing that the government would appear to be “taking over” care responsibilities that more properly belonged to the family. Caregivers also expressed widespread skepticism about the state’s capacity to deliver long-term care benefits to those who needed them. These misgivings took two familiar forms. First, participants expressed concerns about giving too much authority to the federal government:

There’s so many problems like that where the government *does* get into it you know, of accountability. It frightens me, it’s kind of like a loose cannon, it could just go out of control.

[T]here’s so much money that goes to the administration. How much money would actually get down to the caregivers?

The government is so involved in everything in so many parts of our lives. And everything that the government is involved with is, for the most part, poorly run.

In addition to their concern that an extensive government bureaucracy would be an obstacle to the efficient delivery of benefits, caregivers also expressed widespread apprehension that government-sponsored benefits were particularly susceptible to fraud and abuse. Here participants shared a wealth of anecdotal evidence with each other about the many ways in which doctors and medical supply companies cheated Medicare, Medi-Cal, and Social Security. As one caregiver observed to her support group: “[P]eople misuse government money, and they do it blatantly. I think everybody here is Christian,” she said referring to her support group. “We do believe in a deity. So we have some values. But I can’t say that a percentage of people that live in our community have values, and they scam.” Skepticism about the efficacy of government

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<sup>71</sup> Caregivers who explicitly identified as “liberal” Democrats—or in some cases “left of liberal”—were an exception to this rule. Self-identified liberals were strong advocates of universal benefits distributed to all Americans regardless of income.

welfare programs suggested that for many caregivers, their support for state intervention in long-term care was more about practical need than a desire to hand more responsibility over to the state.

The discourse of deservingness, then, may have signaled the expectation among caregivers that state assistance was due to them as “deserving” citizens, but it was couched in a deep cynicism about state authority and government efficiency. In this respect, caregivers’ claims for state intervention appeared to coincide with neither traditional ideological perspective on state provision. On the one hand caregivers rejected a purely residualist approach, clearly making the case that middle-income families needed state assistance for care provision. But on the other hand, most caregivers expressed discomfort with the social insurance approach to care provision as well, insisting that families should take primary responsibility for care provision and that the government should step in only when they cannot meet their basic care needs. Instead of adhering rigidly to ideological distinctions between “entitlements” and “safety nets,” participants in this case blurred these two views: they sought the benefits of an expanded safety net for the middle class under the logic of earned entitlements.

#### *IV. CONCLUSION*

The case of the middle class’s experiences with Medicaid offers important insights into how family caregivers navigate between traditional conceptions and new realities of family life. Most caregivers expect very little from the state when they first begin caring for a family member with a chronic illness. Even after they enter the market for supportive services, caregivers demonstrate a strong normative commitment to keeping the costs of long-term care within the family, paying for supportive services out of pocket, with the assistance of family

members, or in some cases with the help of long-term care insurance. But the costs of market-based care in the United States can be prohibitive, and many middle-income families today simply do not have the resources to satisfy their care needs. Only when these private-sector solutions failed to resolve their caregiving dilemmas did most caregivers in this study look to the state's means-tested Medi-Cal program for assistance. Their experience with Medi-Cal eligibility requirements—set far below the income and asset levels of most caregiver participants—provided caregivers with an opportunity to make a case for how they as citizens *should* be treated by the state and to what benefits they believed they were entitled. Embedded in their justifications for state assistance, in other words, was a coherent set of beliefs that linked their care dilemmas with normative principles about the responsibilities of the state in ensuring the health and economic security of its citizens.

I argue that the ideological justifications for state intervention articulated by most caregivers seeking access to Medicaid reflect an attempt to reconcile their commitment to family care with the contemporary realities of care provision. On the one hand, participants believed that families should bear the primary costs of care provision and that the government should step in only when private resources are insufficient to meet their basic care needs. But on the other hand caregivers articulated *an expansive definition of “need,”* one that envisions not just the poor, but “middle America” as appropriate—and deserving—beneficiaries of public provision. This evolving understanding of “need”—requiring in effect, a much broader, more generous and more inclusive “safety net” for the middle class—departs from residualist understandings of state intervention as temporary, subsistence level relief for the very poor. And yet at the same time, this emphasis on need as a basis for state provision also departs from a social insurance model of

state provision, which typically distributes uniform benefits on the basis of “contributions” or even citizenship status rather than income.

Two observations follow from these findings. First, the fact that caregivers primarily viewed the government as a place of last resort for assistance with the costs of care provision suggests that support for state intervention in this case had as much to do with the weaknesses of private-sector alternatives as it did with the strength of state solutions. This suggests that the broad support for state intervention in this case may be vulnerable to splintering, should private-sector solutions emerge in the future that satisfy the care needs of the middle class. Social scientists have argued that the presence of market alternatives to public social welfare benefits can fracture political support for public welfare programs, as people who can afford market solutions leave the public system, eroding the constituent base available for political mobilization (Esping-Anderson 1985; Hacker 2002; Hirschman 1970; Klein 1983; Oberlander 2003; Stevens 1988). Should the long-term care insurance industry find ways, then, of making insurance policies more available, affordable, and reliable, then political demand for new state entitlements, to the extent that it exists, could diminish. This would leave those caught in the middle—unable to either qualify for Medicaid or afford private solutions—with even bleaker prospects for policy reform.

Second, while both academics and political actors frequently portray contributory and noncontributory approaches to welfare state provision as exhausting all social possibilities (Fraser and Gordon 1992), it is clear that the distinction between the competing political logics underlying these approaches is much less meaningful to Americans trying to find solutions to problems in their everyday lives. The ideological vision of state intervention articulated by caregivers in this case corresponds with neither the residualist nor social protectionist approaches

to social welfare provision. It was clear in this case that for now, market-based “solutions” to long-term care problems articulated by conservative Republicans—such as tax credits for long-term care insurance—are far from adequate for satisfying the care needs of most American families. And yet American families do not appear to be ready or willing to demand the implementation of a social insurance model for long-term care provision. In the next chapter, I consider the implications of caregivers’ political logic—bridging residualist and social insurance models of state provision—for caregiver advocates working in policy arenas with much more starkly defined ideological agendas.

## CHAPTER 5

## THE DIVERGENT EFFECTS OF POLITICAL OPPORTUNITY STRUCTURE ON ORGANIZATIONAL AND INDIVIDUAL EFFICACY

*If it's too hard for people to ask for help for themselves, I think it's nearly impossible for them to ask... for help for everybody. That's something that's so far removed from [caregivers'] realm of consciousness. And I think...from my talking to [constituents] and asking them to come to D.C., they're shocked that they can make a difference. You know, I think most people just say well it's not going to make any difference anyway. So why bother?*

—Jill Kagan, Co-Founder, National Respite Coalition

Thus far, I have argued, following Jane Mansbridge and Aldon Morris (2001) that oppositional consciousness should not be understood as a quality one either “has” or doesn’t “have,” but as a continuum. A *minimal* definition of oppositional consciousness might include a sense of collective identity and injustice. A more fully-developed oppositional consciousness might incorporate an ideology, a well-worked out, internally coherent set of ideas and beliefs that links an individual’s understanding of one’s experiences with values and normative principles relevant to promoting social change (see Oliver and Johnston 2000). While even nonactivists might develop a minimal oppositional consciousness, social movement theorists (Gamson 1992b; Klandermans 1984; McAdam 1982) generally agree that something more is required to persuade individuals to *participate* in collective action: participation requires a sense of *political efficacy*—a belief, as Piven and Cloward (1979, p. 3) famously put it, that individuals “have some capacity to alter their lot.”

In Chapters 2-4, I analyzed the conditions and experiences that give rise to oppositional understandings of care provision—or reinterpretations of private care dilemmas as public problems. In this chapter, I consider why caregivers with oppositional understandings of care provision so rarely *communicate* their views through political or collective action. While many

participants in this study demonstrated a fairly well-developed sense of oppositional consciousness, very few had ever contacted an elected official or participated in any organized, collective effort to obtain policy reforms. I argue in this chapter that caregivers' low participation rates reflect not merely an unwillingness or inability to participate in collective action, as is commonly assumed, but a lack of organizational resources. Without organizations to provide strategic information about when and how they might participate in reform efforts, many caregivers who would otherwise be willing to engage in policy reform efforts feel they lack the opportunities to do so. The absence of perceived organizational advocates in this case is surprising, as not only do many reform organizations in fact exist, but aging organizations such as the AARP are widely considered to be among the largest and most influential advocacy groups in the United States. Yet long-term care reform has not been a priority for these organizations, and relative to social service organizations, advocacy groups play a negligible role in the processes of politicization we have observed so far.

In explaining why advocacy organizations have played such a minimal part in mobilizing families around long-term care issues, I argue that the relatively "new" social needs of families struggling with contemporary care dilemmas pose a particular challenge for reform organizations, as their capacity to mobilize caregivers and influence policymakers is substantially limited by the political structures of the "old" welfare state (cf., Esping-Anderson 1999). Existing systems of social provision—as well as the discursive politics that accompany them—sharply constrain the ability of advocacy organizations to identify caregiver constituents and obtain programmatic solutions that would ameliorate the strains of contemporary care provision. These constraints on organizations in turn affect the perception among individual caregivers that they can "make a difference" through political action.

My analysis in this chapter departs from traditional studies of efficacy, which have largely emphasized *activists'* perceptions of political efficacy, rather than those individuals who are presumably the targets of mobilization efforts. By privileging the views of organizational actors—effectively using the views of activists as a proxy for the views of potential participants—traditional studies of efficacy have tended to miss the ways in which the interests of each group may differ—and at times conflict. In this chapter, I distinguish between *organizational efficacy*, or the perception among activists that movement organizations can alter conditions or policies through collective action, and *individual efficacy*, or the perception among caregivers that their own contribution in collective action can make a political difference. Comparing how activists and caregivers “read” opportunities for political action, I find that not only do perceptions of organizational and individual efficacy differ, but it is this divergence that in part explains why so few caregivers feel they have organizational resources with which to communicate their political demands.

In the following section, I outline the primary approaches used by social movement scholars to studying political efficacy. In Part II, I describe the coding strategies and comparative design used to analyze political efficacy in this case. In Part III, I briefly provide historical and political context for understanding contemporary advocacy efforts for long-term care reform. The analysis of political efficacy in Part IV then takes place in two parts: I first examine how existing systems of social provision limit the availability of family caregivers for mobilization efforts. I then analyze how contemporary welfare state politics limit the ability of advocates to construct solutions to caregiving dilemmas that resonate with caregivers. For each mobilization dilemma, I compare the perspectives of both activists and caregivers, seeking to

identify how their different relationships to the political opportunity structure affect the capacity of caregivers to engage in political reform efforts.

I. *EMPIRICAL APPROACHES TO STUDYING POLITICAL EFFICACY*

Political theorists (Edelman 1988; Gamson 1992b; Merelman 1984) have long observed that there are so many structural and cultural impediments to political participation in the United States, it is not surprising most Americans believe their participation makes little political difference. And yet history is replete with examples of times when individuals have joined together intent on changing the terms and conditions of their daily lives. Social movement researchers have sought to explain how it is that people overcome widespread resignation or quiescence during these historical moments by examining the conditions that give rise to a perception of *political efficacy*.

Variouly identified as “cognitive liberation” (McAdam 1982) or “agency” (Gamson 1992b), the concept of political efficacy generally refers to a consciousness among participants that it is possible for them to alter conditions or policies through collective action. The development of efficacy depends both on the perception that social arrangements long believed to be immutable have become vulnerable to challenge *and* the belief that acting collectively can change those arrangements (Piven and Cloward 1979). As Gamson (1992b, p.7) puts it: conditions must suggest “not merely that something can be done, but that ‘we’ can do something.”

The most common starting point for understanding the conditions that give rise to perceptions of efficacy is an analysis of the “structure of political opportunities,” or what Tarrow (1994, p. 85) refers to as “those dimensions of the political environment that provide incentives

for people to undertake collective action by affecting their expectations for success or failure.” Theorists working in the political opportunity tradition emphasize the role of *exogenous* factors in shaping prospects for mobilization—the relative openness/closure of the institutionalized political system, for example, the presence or absence of elite allies, the state’s capacity for repression, and the power and positioning of various actors within the political environment (Eisinger 1973; McAdam 1982; Tilly 1978).<sup>72</sup>

Researchers have observed, however, that changes in political conditions become “opportunities” only when they are *perceived* as such by movement actors (Kurzman 1996; Meyer 2004; Suh 2001). Doug McAdam’s political process model (1982) was one of the first to explicitly integrate structural factors with social-psychological variables, introducing the term “cognitive liberation” to describe the collective assessment by potential participants of their prospects for successful insurgency (see also Piven and Cloward 1979). The process of cognitive liberation, McAdam argues, is triggered when shifting political conditions supply potential insurgents with “cognitive cues” that the political system is becoming increasingly vulnerable to challenge.

Building on this social psychological approach, social movement framing theorists have sought to explain more precisely *how* this change in consciousness occurs by elaborating the ways in which movement organizations give meaning to events and social conditions to mobilize potential activists and garner support for collective action (see, e.g., Ferree et al. 2002; Snow et

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<sup>72</sup> Some researchers have also recognized a cultural element to political opportunities, noting that culture shapes people’s expectations of political institutions, their understanding of citizenship rights, and their sense of their own power (Gamson and Meyer 1996; Nelkin and Pollak 1981).

al. 1986; Snow and Benford 1988; Steinberg 1999).<sup>73</sup> This perspective holds that social movement organizations produce interpretative frameworks, or collective action frames, that diagnose certain social conditions as problematic and deserving of change, attribute blame or causality for the problem, identify solutions to the diagnosed problem, specify strategies and tactics for obtaining a solution, and, importantly, justify collective efforts to engage in ameliorative action. Such collective action frames are not constructed in a political vacuum, but are themselves influenced by political institutions and power relations: institutionalized interpretations of particular issues, including court decisions and legislative action, make some ideas seem “unthinkable” in a particular time and place, and others seem like “common sense” (Ferree 2003; Steinberg 1999). Because of their role in shaping how individuals perceive their political opportunities for successful collective action, social movement organizations are generally seen as being key actors in establishing a “sense of the possible” for potential participants.

While the framing literature has supplied a crucial link between external political conditions and subjective perceptions of political efficacy, researchers working in this tradition have tended disproportionately to emphasize the strategic efforts of movement *organizations*—rather than those individuals who are presumably the targets of framing efforts (Benford 1997; Futrell 2003; Hull 2001). This tendency to use activists’ views as a proxy for potential participants is in large part a methodological convenience: it is often difficult to ascertain the views of ordinary citizens about the potential for mobilization if they are not actually affiliated

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<sup>73</sup> It should be noted that another approach to understanding decisionmaking about participation takes a rational calculus perspective, examining the process by which prospective participants weigh the anticipated costs of action or inaction against the benefits (see, e.g., Marwell and Oliver 1993; Oliver 1980; Vasi and Macy 2003). Here I rely on a more constructionist approach to social psychology, seeking to understand the processes by which certain lines of action come to be defined as more or less risky, morally imperative despite associated risks, or instrumentally futile (see Snow et al. 1986).

with any movement organizations. But the approach conflates what I argue are in fact two distinct dimensions of efficacy (cf., Benford 1993): (1) the perception *among organizational actors* that movement organizations can alter conditions or policies through specific strategies and actions, or what I refer to as *organizational efficacy*; and (2) the perception *among potential participants* that their own contribution in collective action can make a difference—what I refer to as *individual or personal efficacy*. By privileging the view of organizational actors in framing studies, theorists assume that political opportunities influence perceptions of organizational and individual efficacy in the same way. But activists involved in policy reform efforts are attuned to different aspects of the political opportunity structure than potential participants. Because advocacy organizations lie at the interface of two social arenas—the everyday world of the constituents whom they represent, and the policymaking arenas where they seek to shape programmatic solutions for the problems of their constituents—it is not only possible that perceptions of activists regarding the potential for reform could differ from the perceptions of constituents, but organizational responses to political opportunities could actually *impede* the development of individual efficacy among their constituents.

I suggest that the possibility of divergent—and conflictual—“readings” of political opportunities is particularly likely in contexts involving “new” needs for social provision. Because there is often a mismatch or “structural lag” (Riley, Kahn and Foner 1994) between rapidly changing human lives and social policies, newly emergent social risks faced by constituents may be far removed from the capacity of advocacy organizations to mobilize for programmatic solutions. In this chapter, I consider two ways in which existing welfare state structures can constrain the mobilization efforts of organizations seeking new forms of social provision. First, existing systems of social provision can limit the capacity of organizations to

identify and provide resources to unmobilized caregivers—what I refer to as the “frame bridging” problem. Second, contemporary welfare state politics, itself a product of existing social policies (c.f. Pierson 1994; Skocpol 1992), can limit the ability of advocates to construct politically feasible solutions to caregiver dilemmas that resonate with and address the needs of potential participants (the “frame resonance” problem). I consider each of these in turn.

*The Frame Bridging Problem:* At the heart of framing theory lies an assumption that movement organizations persuade individuals to participate in movement activity by *linking* organizational collective action frames with the interpretative orientations of individuals (Snow et al. 1986). This process of “frame alignment” can take several forms,<sup>74</sup> but the most common is known as *frame bridging*, where a social movement organization connects with unmobilized groups of individuals who share common grievances, but who lack an organizational base for expressing their discontents and acting in pursuit of their interests. Collective action, in other words, requires a structural connection between these “unmobilized sentiment pools” (Snow et al. 1986) and an ideologically compatible movement organization.<sup>75</sup>

To the extent that the political environment makes it more or less difficult for movement organizations to structurally connect with potential participants, we can expect it to affect both organizational and personal efficacy, but in different ways. *Organizational efficacy* depends on a group’s capacity to demonstrate to policy elites the strength and size of their constituency. If organizational actors can neither identify nor reach potential participants for mobilization, it follows they will have a diminished sense of their capacity to alter conditions or policy through

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<sup>74</sup> Other frame alignment processes include frame amplification, frame extension, and frame transformation (Snow et al. 1986). Snow et al. acknowledge that for most social movements today, frame bridging appears to be the primary form of frame alignment.

<sup>75</sup> The appropriateness of viewing micromobilization as largely a bridging problem has some empirical basis, as a number of studies have demonstrated the importance of social networks in understanding movement participation patterns (see, e.g., Friedman and McAdam 1992; McAdam 1986; Snow, Zurcher and Eklund-Olson 1980).

collective action. *Individual efficacy*, by contrast, depends in part on an awareness of opportunities to participate in collective action. Without an organizational base for expressing their discontents and without collective action frames to suggest particular avenues for participation, individuals will likely have a diminished sense of their own capacity to “make a difference.”

In this case, I suggest that existing social policies play a significant role in limiting the availability of family caregivers for frame bridging efforts. Because contemporary care dilemmas are, by the standards of social policy, a relatively new social risk, neither the American public nor systems of social provision are accustomed to thinking about long-term care provision as a public policy issue. With little knowledge about or expectations for long-term care policies, Americans are, as a result, largely unavailable for mobilization efforts *until they are faced with significant care crises of their own*. Once families are enmeshed in the responsibilities of long-term care provision, they have few available public supports to relieve them for the pursuit of other activities. In addition, they remain virtually invisible within the formal health and public benefits systems, which emphasize the needs of *individual patients* rather than family care providers. Caregivers are thus in many ways a hidden constituency, making frame bridging for organizational advocates enormously difficult. While frame bridging dilemmas obviously limit organizational efficacy—as advocates cannot mobilize their constituencies to influence policymakers—they also have consequences for individual efficacy, as some caregivers who are both interested and able to participate in reform efforts may lack any perceived opportunities to do so.

*The Frame Resonance Problem:* The political environment can also differentially affect organizational and individual efficacy by shaping the capacity of organizations to craft

meaningful solutions to the problems of their constituents. The literature on framing suggests that in proffering solutions to social problems, organizations face two, potentially contradictory, imperatives. On the one hand, collective action frames must suggest solutions to problems that are consistent with the ways in which potential participants actually experience those problems—what theorists refer to as *experiential commensurability* (Snow and Benford 1988).<sup>76</sup> But on the other hand, organizations must be attentive to the ways in which collective action frames resonate with dominant political discourse. Ferree (2003) and others suggest that because certain ideas are structurally advantaged or disadvantaged by the terms of dominant political discourse (cf., Diani 1996; Somers and Block 2005), organizations that strategically construct frames to resonate with dominant understandings of certain political issues are more likely to enjoy conventional forms of success, such as winning popular support and elite allies. By contrast, organizations that rely on more “radical” frames—seeking, for example, a more fundamental restructuring of social ideas—are more likely to appear marginal or ineffective.

Here we see an important way in which organizational and individual levels of efficacy may diverge: when organizations try to maximize their capacity to obtain policy reforms by relying on politically-resonant frames, they may marginalize those constituents whose needs and interests are not well represented in dominant political discourse. Without organizational advocates to represent their interests in policymaking arenas, potential participants will likely perceive a diminished capacity to make a difference. Thus, collective action frames that seek to *maximize organizational efficacy* may paradoxically *minimize personal efficacy* among marginalized constituents.

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<sup>76</sup> Snow and Benford (1988) suggest that frame resonance can also depends on at least two other criteria: *empirical credibility*, or the extent to which the framing can be tested for verification, and *narrative fidelity*, or the degree to which proffered framings resonate with the stories, myths, and folks tales that are part of one’s cultural heritage.

In this case, welfare state politics are currently dominated by concerns about the economic costs of existing state entitlement programs. At a time when most welfare states are facing intense economic pressures for austerity, American politics has witnessed a remarkable resurgence in neoliberal attempts to dismantle, or privatize, key aspects of public provision (Hacker 2002; Somers and Block 2005). As the balance of political power has shifted to the right, the range of policy solutions to social welfare programs deemed “legitimate” by the standards of political discourse has contracted: increasingly, market-based solutions are viewed by policymakers more favorably than expansions in state entitlement programs. Organizational advocates who seek to obtain policy reforms, then, must proffer “solutions” to long-term care that resonate with this dominant political discourse. But doing so, I argue, threatens to alienate those constituents who seek more “radical” solutions to contemporary care dilemmas such as expansions in Medicaid benefits for the middle class. In such cases, caregivers who are both interested and able to participate in reform efforts, may believe they lack organizational advocates to advance their interests in policymaking arenas.

In what follows, I compare the effects of the political environment on perceptions of efficacy among both organizational activists and potential participants. I first examine how existing social policies structure the capacity of organizations to identify constituents for the purpose of communicating collective action frames (the frame bridging dilemma). I then analyze how contemporary welfare state politics shape the range of politically feasible solutions available to organizations that might resonate with the experiences of caregivers (the frame resonance dilemma). I begin with a brief description of the methods used to analyze political efficacy in this case, together with some historical context for understanding contemporary advocacy efforts for long-term care reform.

## II. *METHODOLOGY*

Where most studies of political efficacy track changes in political opportunities over time to assess their effects on the likelihood of collective mobilization, here I am interested in comparing how organizational actors and potential participants subjectively interpret the same “objective” political conditions. To analyze perceptions of organizational efficacy I draw on interviews with 29 leaders and key activists from 20 local, state, and national advocacy organizations pursuing long-term care policy reform (listed in Appendix B). As I elaborate in the discussion of methods in Chapter 1, I defined “advocacy organization” broadly to include any organization seeking to influence public policy and resource allocation decisions within political, economic, and social institutions (cf. McConnell 2004). Transcripts from these interviews were analyzed to assess the strategies and goals of each organization, activists’ perceptions of caregivers as a constituency (including characteristics of caregivers that make them more or less likely to mobilize for collective action), and perceptions of the contemporary politics of long-term care policy reform, including the primary obstacles to reform efforts at the state and national levels.

The analysis of caregivers’ perceptions of individual efficacy is based on the observational, focus group, and interview data described in earlier chapters. For this chapter, I coded all caregiver references to policy solutions to long-term care dilemmas and attitudes toward government intervention in long-term care generally, as well as impressions of advocacy organizations and specific reform campaigns. To obtain a sense of how familiar caregivers were with specific advocacy organizations, I presented interview subjects with a list of advocacy organizations and asked them to identify those groups with which they were familiar and to explain how or why they were familiar with them. Finally, I coded all references to histories of

activism generally, as well as activities in which caregivers participated that were consciously intended to improve conditions of long-term care provision for others. As the following discussion will elaborate, some of these activities were organized by advocacy organizations and fit traditional definitions of collective action (such as contacting elected officials or participating in fundraising efforts), while others were actions taken on the initiative of caregivers themselves. Data from organizational actors and family caregivers were analyzed together to assess how each group perceived “political opportunities” for collective action and their capacity to effect changes in long-term care provision.

### *III. THE POLITICAL CONTEXT FOR LONG-TERM CARE ADVOCACY*

Political advocacy around social welfare issues today differs markedly from the decade in which Congress first passed legislation establishing Medicare and Medicaid. A burgeoning economy in the 1960s not only made passage of the Great Society programs possible, but it fostered the expectation among program architects and advocacy groups that Medicare was just the first step toward establishing other social welfare benefits, including universal national health insurance (Marmor 2000; Oberlander 2003). But when the economy soured in the mid-1970s, this expansionary period suddenly ended, and new concerns about the aging of the population and “uncontrollable” health care costs sparked a concerted effort among policymakers to rein in Medicare and Medicaid spending. As a result, advocacy groups who just a few years before had been pursuing an expansion of Medicare to include long-term care benefits, suddenly found themselves on the defensive, fighting to preserve their recently won gains (Hudson 2004).

The political terrain shifted again after the 1994 election, when Republicans swept into control of both houses of Congress. Where in the 1970s and 1980s political discourse

emphasized arguments about how best to preserve entitlement programs in the face of demographic shifts and escalating costs, the core political issues since the mid-1990s have been based more explicitly on *political ideology* and debates about the appropriate role of the federal government in matters of health and social welfare (Hudson 2004; Marmor, Mashaw and Harvey 1990; Oberlander 2003).<sup>77</sup> Conservatives' longstanding public relations campaign characterizing Social Security, Medicare, and other social programs as "fiscal disasters" on the verge of "bankruptcy" gained political leverage in the 1990s, as did conservative "solutions" to social welfare problems: market-based alternatives to public program benefits (such as individual retirement and medical savings accounts) that emphasized time-worn principles of private thrift and personal responsibility. Conservatives also sought to recast the public image of the nation's elderly—long considered deserving and needy beneficiaries—as "greedy geezers" whose powerful Washington advocates protected their extravagant program entitlements at the expense of the rest of American society (Marmor, Mashaw and Harvey 1990; Oberlander 2003; Powell, Branco and Williamson 1996).<sup>78</sup> Far from the political era of liberalism, federal government activism, and social insurance in which Medicare and Medicaid were born, debates about these programs today take place in a political context prioritizing conservatism, decentralizing federal power to the states, and unleashing market forces. Today's advocacy groups face not only persistent concerns about costs, but also ideological attacks that seek to undermine the very principle that the government should be in the business of providing families with health and economic security at all. In what follows, I consider how this political environment shapes

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<sup>77</sup> See also Somers and Block (2005).

<sup>78</sup> The task of changing public perceptions about the relative neediness of the country's aging population was made easier by the fact that their economic position have improved considerably since the 1920s and 30s, in large part because of Social Security and Medicare entitlements (Campbell 2003; Oberlander 2003).

perceptions of efficacy among both organizational advocates pursuing long-term care reform and the individuals they seek to mobilize.

#### IV. *PERCEPTIONS OF ORGANIZATIONAL AND INDIVIDUAL POLITICAL EFFICACY*

##### A. *The Politics of Frame Bridging*

For advocacy organizations to influence policymakers they need to be able to draw on the size and strength of their constituents; for individuals to participate in policy reform efforts they require an organizational base for expressing their grievances and collective action frames to guide their actions. In this section, I examine how existing social policies shape the availability of family caregivers for frame bridging efforts and the consequent effects on organizational and individual perceptions of efficacy. Because the contemporary problems in care provision are the product of relatively recent social trends in market participation, health care provision, household structure, and aging populations, existing systems of social provision (many of which were established half a century ago) have not yet adapted to address the care needs of families facing a shortage in the supply of private care. In the absence of public policies that formally recognize and support family caregivers, advocacy organizations have only a limited capacity to identify and mobilize potential constituents. This affects both activists' perceptions of organizational efficacy, and importantly, caregivers' perceptions of their individual capacity to "make a difference."

##### 1. *Frame Bridging Dilemmas: The Perspective of Advocates*

Activists in this study overwhelmingly observed that the primary challenge of mobilizing for long-term care policy reform is the unusual nature of their constituencies: an overworked and largely invisible population, family caregivers are for the most part structurally unavailable

for mobilization efforts. “Part of why [caregivers are] not perhaps better represented,” observed Gail Hunt of the National Alliance of Caregivers, “is because ... the people who are speaking on behalf of caregivers, can’t really reach back behind them and say here are these millions of people.” Activists offered two explanations for why caregivers were such a difficult population to reach. First, they attributed their constituents’ unavailability to public indifference to long-term care policy and the nature of caregiving itself: before families are in the position of providing care, they have little knowledge of, or interest in existing state benefits for long-term care; but after their care situations have deteriorated to the point where they actually require long-term care support, they are typically too overwhelmed by the responsibilities of care to devote time or attention to questions of policy. Second, activists attributed their constituents’ unavailability to the *structural invisibility* of family care providers in the health care system and public benefits programs. I consider each of these in turn.

Advocates frequently observed that until “it happens to them,” most families are unwilling to think about issues of long-term care provision at all. “[P]eople don’t want to talk about it,” observed Margery Minney, Director of the Valley Caregiver Resource Center in California. “They don’t want to hear about it, they don’t want to deal with it, because at this time it’s not affecting them. And they’re saying it’s not going to. That’s not going to be me.” Rigo Saborio of AARP California argued that the public’s reluctance to discuss issues of long-term care presented a central framing dilemma for advocacy groups:

[H]ow do you create a message, how do you couch it, how do you make long-term care sexy? ... People don’t want to talk about it, you know? And how do you do that so that then it resonates with not only the people who are in it, but also among people not [in it], but may be at some point? How do you make that connection? Because that’s what it’s going to take. That’s what it’s going to take to really push long-term care to the next level.

The challenge of persuading an indifferent public to think about issues of long-term care is made more difficult by strikingly high levels of misinformation in the United States about Medicare. Social scientists have long observed that where in Europe and Canada public consciousness of social policies is relatively high because universal health insurance and child allowances touch citizens' lives every month, the same is not true for most Americans. Medicare, for example, is one of the most popular social programs in the United States (Cook and Barrett 1992), but unless already retired, the typical American has little contact with Medicare administrators, and knows little about the scope of the program or its eligibility rules (Marmor, Mashaw and Harvey 1990).<sup>79</sup> A 1995 survey conducted during the height of a Medicare reform debate (which ostensibly should have raised public awareness about the program) found that fewer than half of all Americans knew that Medicare did not cover long-term care in nursing homes and only 41% knew Medicare did not (at the time) cover outpatient prescription drugs (Blendon, Altman and Benson 1995). Advocates from a wide range of organizations described their constituents as being "stunned" and "shocked" when they realize that Medicare doesn't cover the costs of long-term care. "[T]hey just can't imagine," said Stephen McConnell, the Alzheimer's Association's Senior Vice President for Public Policy and Advocacy, "that something that expensive and that traumatic wouldn't be covered."

Until families are in the position of paying for long-term care, advocates observed, they're not aware that policy reforms might be needed; but by the time families understand what limited sources of social supports are available, they are typically too enmeshed in care provision to participate in efforts to demand additional help. "You're talking about mobilizing people primarily that are absolutely up to their eyeballs with care issues and financial problems and

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<sup>79</sup> Indeed, even retirees report high levels of confusion about the program's coverage (Cafferata 1984; McCall, Rice and Sangl 1986).

disruptions in their lives ....” notes McConnell. Several advocates spoke from personal experience in making the point that most people involved in day to day care provision for a dependent family member cannot think, let alone act, beyond the parameters of their individual situations. Nancy Powers-Stone, Director of the Redwood Caregiver Resource Center in California and a former caregiver for her mother:

It’s very very very very insidious. And a lot of this doesn’t matter how much information you get, it’s just hard, hard, hard, hard anyway. And I think you just get overwhelmed and you just do it. You know, you don’t think that far ahead, you just think day to day. You just get through the day.

From the perspective of advocates, then, one of the primary challenges of mobilizing caregivers is the public’s ignorance of existing long-term care public policy: few people are aware of what contemporary care provision entails or what forms of social provision exist for long-term care until they are faced with a care crisis. As we have seen in previous chapters, such care crises can serve to politicize caregivers. But activists noted that in the absence of sufficient supports, caregivers are limited in their capacity to participate in social reform efforts. Given that so many cannot meet their own physical and emotional needs in such times, it is unlikely that they could take time to participate in political activity.

A second, related obstacle to mobilization articulated by advocates involved the structural invisibility of family caregivers in the health care system and public benefits programs. As we saw in Chapter 2, many family care providers are reluctant to seek assistance from supportive services or make public the problems they face in providing care to their family. Most see care provision as part of their role as a spouse or adult child—a family responsibility—and the shame or guilt of being viewed as a “bad” son or daughter or partner for seeking assistance with caring for a loved one add to the pressure on care providers to keep care problems within the family.

Their reluctance to self-identify as “caregivers,” together with their social isolation as care providers, makes it difficult for organizations to identify who their constituents are.

But in addition to the problem of collective identification, activists noted that there is a *structural* dimension to their inability to readily identify potential participants: the American health care system and public benefits programs typically deliver services and benefits to *individual patients*, without formal assessment of or consideration for their family support systems. Kathleen Kelly, executive director of the Family Caregiving Alliance:

[W]hy doesn't the formal system at least recognize that there's more than one person involved ...? Why don't we ask some questions or recognize that there's more than one patient? ... You do that if you have children. Parents are never left out of the equation for the obvious reasons. But as soon as someone turns 18, it's like well, no one has a family. There's nobody else involved. ... You're just hanging there on your own as a sick person. It's just simply not true!

Because health care services and benefits are organized primarily around the individual patient or beneficiary rather than the patient's family or care providers, there are few formal mechanisms for recognizing the needs of family care providers. In light of this problem, several organizations in this study were active in efforts to develop post-diagnostic guidelines and assessment tools for doctors and service providers which would formally connect families with services and benefits in the community.<sup>80</sup> Janet Morris, an attorney at Bet Tzedek Legal Services, was part of such an effort in Los Angeles:

[A]ll a physician has to do is give a number to their client who has dementia that says call the Alzheimer's Association and that's the gateway, the true gateway, to services. ... If all they did was that, I think it would ...make a huge difference in how people are treated and what access to services they have.

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<sup>80</sup> Gail Hunt of the National Alliance for Caregiving observed that while caregiver advocates are strongly in favor of establishing uniform assessments, policymakers are generally wary of the idea, in large part because of the social policy implications for what such assessments might find: “If you assess me, you've got to have something to offer me, right? Now that you know that I need this stuff, what are you going to do about it?”

Without a formal mechanism for linking families, rather than individuals, to public services and benefits, advocates argued that the caregiving population was an effectively invisible constituency, one that could not be mobilized by traditional methods of organizational outreach. As Gail Hunt, Executive Director of the National Alliance for Caregiving observed: “You can’t mobilize the caregivers across the country by zip code or congressional district. ... In terms of advocacy, that’s the issue ... the fact that ... there’s no easy way to reach them really makes it hard to make a case.”

In the absence of public policies that formally recognize and support family caregivers, activists viewed their capacity to identify and mobilize potential constituents—and to demonstrate to policymakers the strength and size of their constituencies—as seriously compromised. But constraints on frame bridging not only shaped perceptions of organizational efficacy: as the following discussion illustrates, without collective action frames—or any known organizational advocates—caregivers’ sense of political efficacy was also affected. Most caregivers in this case neither knew what could be done to improve public policies for families providing long term care, nor did know what *they* could do to help.

## 2. *Frame Bridging Dilemmas: The Perspective of Caregivers*

Whereas activists in this case largely depicted American families as being either uninterested in or unavailable for collective action, here we find that caregivers’ nonparticipation is less about being unwilling or unable to participate than it is about not being *asked* (cf., Verba, Schlozman and Brady 1995). Activists’ understanding of caregivers as being ill-informed about public policies and too busy to participate in reform efforts is true for many caregivers, but it does not explain the sizeable group of caregivers in this study who devoted considerable time

and energy to the task of helping other families in long-term care dilemmas. Nor does it explain those caregivers who had not participated in any form of activism but who expressed a willingness to do so. I attribute the low rates of participation among these caregivers instead to the absence of collective action frames.

Caregivers largely confirmed advocates' perception that most people know very little about long-term care support systems until they become personally involved in caring for a family member with a chronic disease or disability. Many caregivers admitted they had never heard of services like adult day care before their family members required such assistance, and most had no idea that virtually all supportive services, including nursing home care, are not covered by Medicare or private health insurance policies. Nick, for example, was 53 years old when his father fell and required emergency brain surgery. After the operation, the surgeon informed him that his father was exhibiting symptoms of Alzheimer's disease, and that his condition was serious enough that he would likely have to be institutionalized. Nick's description of what unfolded at the hospital is typical of many adult children caring for their parents:

[A]t first I thought I was getting the runaround from the hospital ... because they told me ... the day I was there that we have to release your father. And I said, well couldn't you have given me a heads up a week before? ... And they said to me oh you know that Medicare is 20 days. And I said I've never even seen a Medicare book! I said I'm not 65 yet, I don't know about Medicare!

Caregivers frequently observed that most of the people they knew had no idea Medicare did not pay for nursing home care. Carolyn was 57 when her husband began suffering from the beginning stages of a rare degenerative brain disorder.

I think most people think that you put somebody in an institution and the government's going to pay for it. Well that's not true. And we don't know that until the issue comes up. ... And all the help that you think you could get? You

don't. You have to pay for it. ... I don't think people understand this. ... I can't tell you how many times [people] say well you can always put him into an institution. Well no you can't. No you can't. And that's the fact of life. And people don't know that.

As previous chapters have elaborated, family care providers generally develop a more nuanced understanding of long-term care policies through the experience of caregiving itself—typically after they seek assistance from supportive services.<sup>81</sup> But most family care providers seek out social services relatively late in their caregiving careers, and often when their caregiving situations have deteriorated to the point where some crisis has ensued.<sup>82</sup> As one social worker at the LA Caregiver Resource Center observed: “[P]robably 98% of all the calls here are because ... the shit's hit the fan.” When asked why they think more families haven't pressed for more governmental assistance, caregivers emphasized this sense of crisis:

[Caregivers] are so involved with taking care of their family members, they probably just can't think of the concepts or the things that are bothering them....I do think it's we're so burned out. ... It's being overwhelmed.” (Nick, 55)

They're so busy they can't communicate! (Carolyn, 53)

You have what you have the stamina to fight for at the time. And if I look around the table at some [support group] meetings, I know that some of those people may or may not have the stamina left to do some of that. Because it wears you down. It wears you down. (Flora, 50)

There is some evidence, then, to support the conventional wisdom that caregivers are too busy or overwhelmed to participate in collective action. And indeed, of the 79 caregivers interviewed in this study, only 6 individuals had contacted an elected official about a long-term care issue. Another 7 individuals had participated in fundraising efforts or other activities

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<sup>81</sup> However, the length of this “educative” process varies—some people are quite suddenly thrust in the caregiving role because of some defining event—a stroke, a heart attack, an accident, a botched operation. Others may quite gradually take on caregiving responsibilities over a period of ten or more years.

<sup>82</sup> According to advocates interviewed in this study, the time between diagnosis and first contact with a Caregiver Resource Center or an office of the Alzheimer's Association is approximately two years in the State of California.

organized by an advocacy group related to a long-term care issue. But there is also evidence to suggest that the stress of caregiving is an incomplete explanation for low levels of participation: an active minority of those interviewed were both willing and able to participate in collective action, but were unaware of any opportunities to do so. This group included: (1) caregivers who had engaged in individual—rather than coordinated or collective—forms of activism, a group I refer to as “individual activists”; and (2) nonactivists who indicated a willingness to “do something” but lacked any ideas about what that something might be. In both cases, caregivers indicated an availability for participation, but an absence of collective action frames to orient them toward collective goals and actions.

Over a third of those caregivers interviewed had participated in *individual activism*—actions taken on their own initiative that were consciously intended to help other families dealing with long-term care issues. One individual, for example, responded to the closing of an adult day care in her neighborhood by starting a foundation that not only re-opened the facility, but helps subsidize day care for other families in her community. Others sought ways to assist caregivers by writing for caregiver newsletters and distributing literature about supportive services in doctor’s offices, libraries, churches, and other settings. Two caregivers attended training sessions to become support group leaders themselves. Still others remained active in support groups even after their caregiver roles had ended, in the hopes of helping “new” caregivers navigate the challenges of long-term care provision.

All of these actions were described by respondents as conscientious attempts to use their caregiving “expertise” to help other families through the challenges of long-term care provision. Dora, for example, was a former caregiver for her mother and among the most politically active

participants in the study.<sup>83</sup> Prior to her experience caring for her mother, she says, she had no special interest in caregiving. It was her exposure to the LA Caregiver Resource Center, where she attended a support group, received counseling, attended workshops and classes, and a 48-hour caregiver retreat, that she says made her such an active participant: “I just learned so much ... in terms of coping skills, ways in which to strategize and to accept the situation that I was in. ... And even after my mother’s death, I felt a sense of family and wanting to contribute to those who are in the throes of caregiving.”

Tony, a caregiver for his wife, routinely passed out information on caregiving and Alzheimer’s disease to people in his church and other places in his neighborhood. “I just feel we need to go down and start teaching these young people about what’s coming in the future.” In his mind, experiential knowledge is among the most persuasive tools there is for effecting change:

[I]t’s so valuable to get out to people because as the younger [generation] says, you walk the walk and talk the talk. So it’s not something that somebody said distant or that somebody printed in the paper. What you says is the truth because it comes from you and you lived through it. And I really think that’s where the value of it is.

Many of these caregivers explained that they wanted to use their experiential knowledge to make sure others didn’t suffer as they had. “I’m taking some pleasure in passing on information to other people,” observed one recently widowed caregiver. “I [was a caregiver] for six years, although the hardest 24-7 part was the last three years. I tell people get help as fast as you can and as much as you can! ... Don’t wait until you are on complete overload.” Indeed a handful of caregivers gave this reason for participating in this study: “I just hope it helps

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<sup>83</sup> She has attended a training class to lead her own caregiver support group, she has traveled to Sacramento twice for “advocacy days,” and at the time of this study she had been asked to testify in a legislative hearing on caregiving and to join an advisory council at a USC Alzheimer’s research center.

someone,” one woman told me at the end of her interview. “Because I would not like to see anybody else go through this.”

The fact that nearly 40 percent of the caregivers interviewed had participated in either individual or, more rarely, collective activism around long-term care issues, suggests that advocates’ perception of caregivers as either too indifferent to long-term care policy or too overwhelmed by caregiving to be politically active, dramatically oversimplifies the relationship between participation potential and the caregiving experience. Caregivers’ experiences suggest instead that participation potential fluctuates over the course of the caregiving career. As Figure 1 illustrates, before the caregiving experience begins (point A) participation potential is, as both advocates and caregivers indicated, typically very low, due largely to lack of information about or interest in long-term care issues.

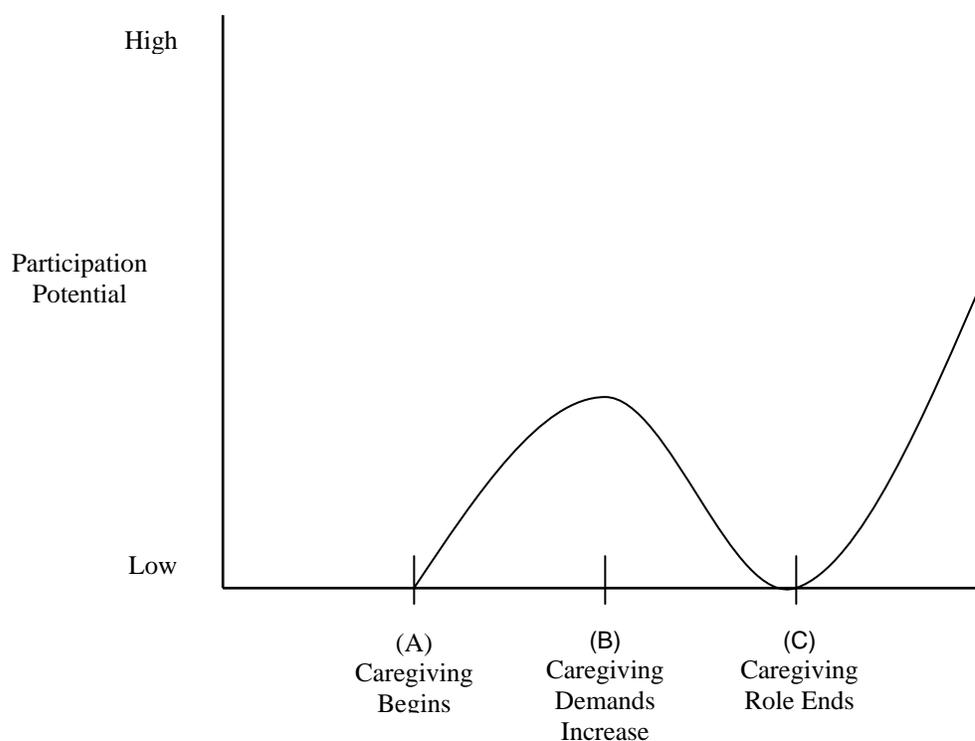


FIGURE 1: PARTICIPATION POTENTIAL OVER THE CAREGIVING CAREER

But between the point at which caregiving begins (A) and the point at which caregiving demands have reached a “crisis” stage (B)<sup>84</sup>—i.e., when individuals can handle nothing more beyond care responsibilities—there is a period where individuals both obtain more knowledge about long-term care policies and have a vested interest in reforming such policies, increasing the likelihood that they may participate in some form of activism.<sup>85</sup> In this study, over half of the caregivers who described themselves as taking some form of conscious action to help other family care providers were stage A-B caregivers: they were active caregivers with an interest in obtaining long-term care public benefits, but were not overwhelmed by the emotional or physical responsibilities of caregiving.

As care provision demands more time and energy of caregivers, participation potential decreases. A nonstatistical comparison between those caregivers who pursued some form of activism and those who had not, illustrates the largely intuitive correlation between demands on time and participation potential.<sup>86</sup> Activists tended to have fewer demands on their time than nonactivists. More than half of the nonactivist caregivers were providing care to people who needed assistance with more than three “activities of daily living,”<sup>87</sup> whereas only one-third of caregiver activists were providing comparable levels of care. Nonactivists were also more than

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<sup>84</sup> The “crisis” stage is a highly subjective one, as individuals vary in the kinds of emotional, physical, social, and financial resources on which they can draw to manage caregiving situations.

<sup>85</sup> Note that this model is merely a heuristic device and is not meant to be representative of all caregiving experiences. Caregiving situations, for example, that begin with a sudden incident such as stroke, would show virtually no space between points A and B in the caregiving trajectory.

<sup>86</sup> Notably, the likelihood of participating cannot be attributed to any traditional indicators associated with political participation such as higher levels of income, education, age, or history of activism. Indeed, nonactivists tended to have somewhat higher incomes than activists: Sixty percent of *nonactivists* had incomes over \$50,000, compared to just 41% of caregiver activists. Levels of education were roughly equal between both groups, and the average age of both groups was the same (63). Both groups had relatively similar histories of activism—42% of nonactivists and 50% of activists had engaged in any kind of collective or political actions in the past.

<sup>87</sup> “Activities of Daily Living” are activities involving personal care, such as eating, toileting, getting in and out of bed and chairs, bathing, dressing, and grooming, and managing continence.

twice as likely to be balancing care provision with full-time employment outside the home. These findings are consistent with the argument that as demands on time increase, we can expect participation potential to decrease.

But once the caregiving role has ended (C)—with the death or recovery of the care receiver, or termination of the caregiving role (i.e., when the caregiver hands over care responsibilities to someone else)—the potential for participation again increases. As with more famous caregivers who went on to become activists—Rosalyn Carter, Nancy Reagan, Dana Reeve—the caregiving experience itself can be a politicizing one in which participants seek out ways to help other families after their caregiving role has ended. Nearly a third of the caregivers who described themselves as taking some form of conscious action to help other family care providers were former caregivers. Indeed, it is this group, more than any other, that over time would seem to represent a significant constituency for mobilization efforts.

The argument that caregivers are too busy for participation in collective action, then, does not explain the sizeable group of caregivers who devoted considerable time and energy to the task of helping other families in long-term care dilemmas. Nor does it explain those caregivers who had not participated in any form of activism, but who expressed a willingness to do so. One caregiver's response to my inquiry about participation in collective action typifies this group of potential participants: "I have researched the hell out of this [disease]. And made sure that we've seen the top specialists. But not on a political level. But I would. You want me? Call me." When asked whether they had ever contacted an elected official about a long-term care issue, many of these caregivers' responses made clear that the idea had simply never occurred to them. "[T]hat is a very good question," said one caregiver, who is active in local politics about other issues, "because at the very least ... a handwritten letter from me would have the force of

500 people. So, yeah, I should.” Another caregiver, interviewed during the campaign for Los Angeles mayor, responded similarly: “I never thought about it. My sister and I would probably think about it. [It] may be something that we should speak with someone about. Maybe some of these that are trying to get in as mayor. Maybe they’ll have an open ear.”

These caregivers’ reactions hint at an alternative explanation for why so few caregivers had participated in any form of political or collective action: many caregivers had never been asked to do so. Asked if she had ever contacted an elected official about a caregiving issue, Linda’s response is typical: “No...But you know what? I really should. I really should. It’s just that I don’t know what to ask for. You know, find a cure for Alzheimer’s? ... Help us take care of our parents who have Alzheimer’s? I don’t know what to ask for.”

The apparent absence of collective actions frames among these participants illustrates the *inverse* frame bridging problem discussed by advocates: where advocates bemoaned the challenges of identifying family caregivers to mobilize, caregivers complained about lacking organizational advocates. Caregivers saw advocacy organizations as playing two important roles: informing elected representatives of their needs and interests and advising caregivers about strategic opportunities for collective action.

I know there’s lots of lobbyists in Washington that are tuned in to the special interests over there, such as tobacco and drugs and so forth. ... I don’t know of anything that’s up there that’s really representing caregivers at all. (Isadore, 72)

I think that’s an area where we really don’t know what’s going on in Congress. What acts are coming up and what’s been considered. Unless there’s some kind of watchdog organization that was advising ... you could have nothing to do with any kind of legislation. (Jill, 53)

That caregivers were unaware of advocacy organizations seeking policies to assist families in long-term care provision, could be seen in the low levels of name recognition among

many of the organizations in the sample. Respondents were least likely to recognize caregiving-focused organizations: four out of five caregivers interviewed (80%) had never heard of the National Alliance of Caregivers; more than 9 out of 10 caregivers (92%) had never heard of the National Family Caregiver Association. Local advocacy organizations that were engaged at least partly in social service provision fared relatively better: just over half of the sample had heard of the Los Angeles Caregiver Resource Center (54%) and Bet Tzedek Legal Services (51%).

While nearly all of those interviewed recognized the much larger Alzheimer's Association and the AARP, few caregivers knew what these more well known organizations were doing to advance reforms around long-term care. In a peer group discussion about proposals for public policy supports for caregivers, Tony articulated this concern:

How does the Alzheimer's Association view this, or have they been approached with the question of what would be best for caregivers? Has any national organization been approached or do they know about the problem? ... I really don't think that besides us in this room, there's too many people know what's even going on here.

Another group discussion on public policies produced similar queries from other caregivers:

It sounds like what we're talking about here is there's no grassroots movement, you know? We have the AARP, and they're certainly not a radical, get-out-the-vote group. And what happened to the Gray Panthers? For a while they were around, but I haven't heard of them. So there's ... no organization, and I don't know why.

Taking into account both organizational *and* individual levels of analysis, then, we see that both activists and caregivers articulated frustrations over the possibilities for mobilizing family caregivers in reform actions, but their perceptions of efficacy were derived from different sources and had different implications for the mobilization potential of family caregivers. For activists, structural limitations on frame bridging were understood as a significant constraint on

*organizational efficacy*: focused on their ability to “reach behind them” and draw on the strength of numbers to pressure policymakers for reform, activists viewed caregivers as unavailable for, or invisible to mobilization efforts. For caregivers, by contrast, the frame bridging problem affected perceptions of *individual efficacy*: in the absence of collective action frames—or any known organizational advocates—caregivers neither knew what could be done to obtain policy reforms, nor did they know what *they* could do to help. Thus, from the perspective of caregivers, low participation rates reflected not a lack of politicization, but a lack of perceived opportunities to engage in reform efforts.

The movement inertia produced by constraints on frame bridging efforts, however, explains only those instances in which organizations fail to connect with family caregivers. Clearly, frame bridging problems weren't universal—we saw, for example, that while name recognition of some organizations was quite low among family caregivers in this study, nearly all participants had heard of the AARP and the Alzheimer's Association, and half of the participants had heard of local organizations such as the LA Caregiver Resource Center. Why weren't participation rates in collective or coordinated social action higher among these caregivers? I next consider the effects of the political environment on the ability of organizations to construct resonant solutions to the dilemmas of contemporary caregivers.

### *B. The Politics of Frame Resonance*

If existing social policies make it difficult for organizations to identify and mobilize families around contemporary care issues, they have also contributed to a political context that sharply constrains the range of “legitimate” solutions available to advocates for the problems of their constituents. Contemporary welfare state politics in the United States, as in most modern

welfare states, center around the highly contentious issues of how to preserve, restructure, and/or modernize existing governmental commitments in the face of global economic austerity, aging populations, and the rising costs of health care. In the United States, the debate over the costs of welfare state policies is contentious in part because of divergent ideological views on the role of the state in safeguarding the health and economic security of American citizens. While proponents of both the residualist and social protectionist views are represented in political discourse, the balance of power in the United States has shifted markedly to the right over the past decade, and as a result certain framings of welfare state “solutions” have considerably more influence in political discourse than others—most notably, framings that emphasize market-based solutions to social welfare problems and which avoid expansions of public entitlement programs.

The formulation and communication of political demands for long-term care public policy reform takes place within this political context, and I argue that the divergent ways in which advocates and potential participants evaluate the political environment explains why so few caregivers perceive themselves as having organizational advocates. Advocates seeking long-term care policy reform are attuned to those aspects of political discourse that structure the political feasibility of particular goals and strategies, as their success in policymaking arenas depends to a large degree on the extent to which their proposals resonate with dominant political discourse (cf., Ferree 2003). By this standard, advocates largely viewed the political opportunity structure as “closed” to any efforts to expand government entitlements in ways that would meet the needs of their constituents. Caregivers, by contrast, were less influenced by the economic and ideological arguments against expanded entitlements that dominate political discourse and much more concerned with what kinds of policies would ameliorate the care provision strains

they faced on a day to day basis. To caregivers, in other words, organizations promoting policy goals that resonated with dominant framings of “legitimate” solutions, were viewed as doing little to represent caregiver interests in policymaking circles. In what follows, I elaborate these two divergent views of the political environment in greater detail.

*1. Frame Resonance Dilemmas: The Perspective of Advocates*

In Chapter 3 I argued that the one caregiving issue which most clearly rose to the level of a grievance—or injustice—for caregivers in this study was middle- and working-class eligibility for Medicaid long-term care benefits. The caregivers who could neither afford to purchase supportive services nor qualify for public assistance under Medicaid without spending down their lifetime’s savings consistently decried their denial of public benefits, making a case that it was the government’s responsibility to protect people from falling into destitution over circumstances beyond their control. “I think it’s unconscionable for any country to call itself civilized and put liens on people’s homes because they had the wrong disease,” said Patricia McGinnis, Executive Director and founder of California Advocates for Nursing Home Reform (CANHR), capturing this point of contention among caregivers. “If I needed a heart transplant, I could go in the hospital, Medicare would cover it. But I have Alzheimer’s. I go into the nursing home and I have to pay privately until I’m down to \$2,000 and then wipe out all my assets, and then I can go on Medi-Cal.” I posed the problem of middle-class Medicaid eligibility to all of the advocates interviewed for this study to find out what kinds of “solutions” their respective organizations had proposed for the problem about which caregivers spoke with such heated indignation. The responses from advocates painted a picture of a political environment that constructed certain policy solutions—namely, entitlement expansions—as “unthinkable” and other, market-based solutions as politically “realistic.”

Describing 2004 as a “marathon year” in terms of defensive campaigning, advocates widely observed that their organizational priorities had in large part been set by the Bush administration’s social welfare priorities: privatization of Social Security, Medicare Part D drug benefits, and Medicaid cuts (including tightening eligibility requirements for long-term care benefits). Within this political context of defensive organizing, any significant expansion of public benefits programs was understood, as one legislative analyst put it, as “lower on the totem pole of things that are urgent.” Thus, proposals to expand Medicare to include long-term care benefits, or to expand Medicaid to permit eligibility for the working and middle classes were widely viewed as “off the table” for discussion. “We don’t talk about this a lot,” said Michael Connors of CANHR on the issue of middle class entitlements, “because a lot of this is beyond [what we can] achieve for the moment.” Stephen McConnell of the Alzheimer’s Association stated the issue more bluntly: “[T]he harsh reality is that trying to get a new social insurance program to cover long-term care is not likely in my lifetime.”

Asked to explain more specifically what about the political environment foreclosed the possibility of any substantial government interventions in long-term care for the middle class, activists suggested that policymakers were primarily concerned with the economic costs of *existing* government entitlement programs, and that these concerns had substantially changed the tenor of ideological debates about social welfare provision. At the state level, advocates observed that in the face of ballooning Medicaid costs, legislatures were far more likely to *cut* benefits than add them. At the federal level, activists noted how past experiences with escalating costs of both Medicaid and Medicare had left a lingering trepidation among policymakers about introducing any new entitlements. Diane Lifney, a legislative analyst for the National Committee to Preserve Social Security and Medicare who has worked on Capitol Hill for 24 years, noted

that even policymakers who are supportive of social insurance programs are gun-shy about new benefits for this reason:

I think policymakers are afraid of starting a program that ... might sound okay today, but who knows what it's going to grow to? Because they've seen it happen with other programs. ... [O]nce you have a program in place, then people keep wanting to expand it. And you know, costs go up, and it's not what it ... started out being. I mean I saw that way back with more liberal Congresses...It's still oh, what are we signing up for here?

While activists generally perceived the costs of existing entitlement programs to be a bipartisan concern, political “solutions,” they argued, were ideologically charged and generally reflected the rightward shift in the balance of power in the United States. “When I hear Republicans talk about this issue,” observed Gail Hunt of the National Alliance for Caregiving, “I hear them say yes, there should be a safety net for poor people. Everybody agrees on that. But why should middle class people expect the government to pay for their long-term care?” Michael Connors of California Advocates for Nursing Home Reform observed that the prevalence in contemporary political discourse of a free market ideology which conceptualizes government as “the problem” and private markets as “the solution,” made it very difficult for progressive organizations to find legislative champions for substantial long-term care reform.

As long as we're focused on attacking and shrinking government—and there's so much public support of those folks who [are] reigning in government—trying to find politicians who are willing to advance something that's very ambitious, that changes the whole way we look at the issue, is enormously challenging.

The ideological cousin of free market discourse—the notion of personal responsibility—was similarly seen as a substantial constraint on the range of opportunities for reform. Kathleen Kelly of the Family Caregiver Alliance noted that the philosophy of personal responsibility had permeated the health care field. “I think it's enormously dangerous. ... [I]nstead of looking at

[long-term care] as a societal issue, what do we do about it as a community rather than an individual effort, this whole individual effort dismantles societal responses.”

Acknowledging that expanding government entitlements for the middle class was politically “unthinkable” in the current political context, advocates conceded that there were few available policy solutions that would offer substantial financial assistance for the nonpoor.<sup>88</sup> “[W]hat would middle income people benefit from?” asked Kathleen Kelly of the Family Caregiver Alliance. “I don’t mean to sound like I’m at a loss for ideas, but ... you can muddle around the middle, you can do these little add-on kinds of things, but the big nut is what’s happening on a daily basis? And I don’t see how anyone’s really addressing that.” For most organizations, scarce resources generally precluded sponsoring ambitious policy proposals “just for the sake of letting people know that we’re trying.” As a result, activists struggled to find a way to balance the needs of their constituents with what one activist referred to as “the art of the possible.” Stephen McConnell, Senior Vice President of Public Policy and Advocacy at the Alzheimer’s Association, spoke at some length of his organization’s efforts to weigh these competing concerns. In setting their agenda, he said, leaders at the Alzheimer’s Association first solicited input from the organization’s board and from chapters around the country:

[W]hat’s the best thing for the people that we represent and for the future of the country? And then we take that and we mush it into the current political environment, and we say what do we think we can get done on those issues in the next year, three years, five years? And we developed an advocacy strategy ... [T]his year’s been really defensive. It’s been about protecting Medicaid...and to keep from going backwards on various health care policies. ... So it’s a constant back and forth iterative process between what our constituents need and what’s possible.

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<sup>88</sup> The National Committee to Preserve Social Security and Medicare is one of the few organizations in this study to take a definitive position on the issue of long-term care, outlining a set of principles that called for a comprehensive national social insurance program. Legislative analyst Alison Bonebrake explained her organization’s position: “We thought that ... proposals that were in Congress ... the tax credit and tax deductions ... only helped those that were able to really afford it. And that Medicaid isn’t the appropriate safety net for long-term care.”

Several advocates acknowledged that to the extent organizations prioritized political feasibility, they faced a potential diplomacy problem with constituents. Rigo Saborio of AARP California, for example, noted that most of his organization's members clearly wanted an expansion of long-term care public supports.

[B]ut you know, the reality is, is that we recognize that we're not in a time to be able to expand. And we certainly do get engaged in meetings where people are seeking our advice and ... we have to sort of say, reading tea leaves, this is not the right time to do it. [W]e have to resist the temptation of trying to get into a battle that's so extreme that you're not really going to win. ....We recognize that the time to go after more is not now. We ... want to make sure that we don't lose what we have obtained up to this point. So that's where our efforts are. That's what our message is, to not only our members but to partners out in the community.

While it was clear that organizational actors were attuned to the needs and interests of their constituents, it was also apparent from their proffered "solutions" to long-term care problems that political feasibility was a paramount concern. Policy proposals endorsed by most organizations involved modest, incremental, solutions that involved relatively little cost to the state.<sup>89</sup> Kathleen Kelly, Executive Director of the Family Caregiving Alliance, reported that the legislative priorities for the Family Caregiver Alliance included reinstating California's modest \$500 tax credit for caregivers, which lapsed in January 2005 due to legislative inaction, and pursuing uniform caregiver assessment guidelines for identifying caregiver support needs in service delivery settings, a proposal that involves relatively few state dollars. CANHR's current policy priorities include several nursing home rights initiatives and dedicated complaint response

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<sup>89</sup> The NCPSSM could be considered partial exception here. The organization supports Senator Kennedy's "Class Act" legislation, which calls for a new long-term care social insurance benefit. However, its campaigns over the past several years to defend Social Security and Medicare from privatization efforts and to defend Medicaid from budgetary cuts have meant that the organization has not been able to devote any significant resources to pursuing that legislation.

units. “That shouldn’t cost any more money,” Executive Director, Patricia McGinnis observed. “It’s just a matter of reorganizing the staff that they’ve got in the district offices.”

If the political environment could be seen as constraining the range of solutions progressive reform organizations proposed for long-term care problems, it could also be seen as influencing their positions on conservative proposals for long-term care policy reform—which most frequently involve tax credits for long-term care insurance. Where progressive advocacy groups had once been staunchly opposed to reform proposals involving long-term care insurance on the grounds that even with tax credits, very few working- and middle-class Americans can afford long-term care insurance, many have eased their opposition in recent years in the hopes of obtaining even incremental relief for some American families. Nowhere is this strategic transformation more evident than in the Alzheimer’s Association. For years, the Alzheimer’s Association had relied on an injustice framing strategy to make a case for expanded entitlements for the middle class. “The issue was very much to try to tap into what is probably a civil rights sense, that ... it is an outrage, it is unfair, it is discriminatory, that people have to impoverish themselves to get help,” said Stephen McConnell. But, he said, the strategy ultimately backfired: after years of characterizing Medicaid as an unfair system of welfare, advocacy organizations found themselves in the position of *defending* Medicaid benefits against cuts. “[T]hat’s as far as the debate has gone. It has not in any way advanced beyond Medicaid and some private insurance.” As a result, McConnell noted, the position of the Alzheimer’s Association on the role of private insurance has gradually changed. “We ... were quite critical of private insurance, for the reason that we felt that once private insurance got a foothold, it would be very hard to do anything else.” But in the current political context, in which entitlement benefits are considered “off the table” for discussion, private insurance, he argued, “is the reality.” “I think the deals

we've made have to do with okay, we'll support tax incentives for private insurance if the insurance industry will support tax credits for caregivers. Calling that long-term care policy is you know, a huge stretch of the imagination, but it's all about trying to move the agenda on an incremental basis."

Activists observed a political environment, then, in which economic and ideological concerns about existing systems of social provision severely constrained the range of policy goals they could endorse if they wanted to successfully obtain relief for any of their constituents. As a consequence, organizational advocates proffered policy solutions that resonated with dominant political discourse, even as they were aware that these solutions did little to alleviate the more pressing, day-to-day concerns of working and middle class family caregivers. In the parlance of social movement theory, the imperatives of political resonance weighed more heavily on decisions about goals and strategies than the imperatives of experiential commensurability. I argue below that these decisions had important consequences for perceptions of individual efficacy among many family caregivers. Largely unpersuaded by the economic or ideological arguments against expanded entitlements that dominated political discourse, caregivers instead perceived the policymaking world as a contest among interest groups in which their needs and interests were not being effectively represented.

## *2. Frame Resonance Dilemmas: The Perspective of Caregivers*

If economic and ideological constraints posed significant dilemmas for organizational actors, they factored very little into caregiver analyses of political opportunities for reform. Only a handful of caregivers believed that the government could not afford to take on a substantial role in subsidizing long-term care provision for American families because of issues of cost. "To expect [the government] to be more supportive financially with these things," noted one

caregiver in this regard, “I just don’t see economically how that’s feasible.” These caregivers typically expressed support for a long-term care safety net, but thought it unreasonable to demand universal entitlements: “I used to believe that everybody should have the same access. That was one of the main principles behind Social Security. But with a deficit of whatever it is, it’s just not feasible . . . .”

But most caregivers in this study were not persuaded by arguments that the budget deficit, skyrocketing health care costs, or fiscal “crises” in Medicare and Medicaid limited the government’s capacity to help families with long-term care provision. For the most part, caregivers perceived these problems to be the product not of market forces, as political rhetoric suggests, but of political choices. “I think it’s the attitude of our government,” noted one caregiver who expressed this common view. “All the other countries in Europe and everywhere else have made ways to do things for their people . . . . But we don’t. We want to take back a lot of the stuff and we’re spending money on things that aren’t helping us. . . . [T]here’s agendas that are going on for the people that we put into office. And they have nothing to do with the people.” Caregivers thus largely dismissed the idea that the government could not afford to help subsidize the costs of long-term care, arguing instead that the availability of funding for health benefits was a function of the government’s spending priorities. The following comments are representative in this regard:

[W]e’re the greatest country in the world. . . . The United States has money for everything else. But for our elderly who need it, when they need it, it doesn’t seem to be there. And it’s not right. Congress, whatever, they need to be more involved in the process. (Mary, 55)

I know that I’m saying what some people may be thinking, but if we weren’t supporting a very expensive, unneeded war, we could put a lot more money into the health needs of people . . . (Leda, 65)

We do need a strong defense. And I agree with that. But a stronger people, you know, how can we sell the United States around the world and you draggin' black people behind pickup trucks? You got seniors going and doing without?  
(Tony, 72)

Caregivers' views were similarly unaffected by ideological objections to an expanded government role in long-term care provision. Conservative rhetoric that public solutions to health security problems, embodied in programs like Medicare or Medicaid, were, *as a matter of principle*, uncontrollable and undesirable, was largely dismissed by most caregivers in this study. As Chapter 4 illustrated, the practical need for financial assistance among working- and middle-class caregivers overrode any ideological objections to an expanded state role, such that even caregivers who identified as political conservatives were supportive of an increased role for the state.

This view of government as constrained only by the choices of individual politicians regarding the allocation of public resources reflects a perception of political conditions as more mutable, more vulnerable to challenge, than that described by activists. From the perspective of caregivers, solutions to their long-term care financial problems could reasonably be obtained, if only politicians could be convinced to prioritize the needs and interests of families providing long-term care. In this regard, caregivers described a political environment that closely corresponds to a classic interest group model of policymaking, in which policymakers allocate resources based on the relative influence of particular constituencies. Because caregivers looked to advocacy organizations to inform policymakers of the needs of families providing long-term care, their perception of political efficacy depended less on the perceived openness of the political environment, than on how adequately advocacy groups appeared to be representing their interests.

Caregivers in this study assessed the representational capacity of advocacy groups primarily by evaluating how closely the known goals and priorities of these organizations matched onto their own. In a few instances, caregivers perceived a congruence between their interests and organizational advocacy efforts: Reba, for example, who had frequently expressed concern about the Bush administration's privatization efforts with regard to both Medicare and Social Security, applauded the work of the National Committee to Preserve Social Security and Medicare, noting that she tried to send the organization donations as often as she could. "[I]f we don't have that, the people don't have Medicare and all that, we're really in trouble," Reba argued. "But they're really pushing in Washington there."

But more often, caregivers perceived organizational efforts as inadequate, or even inapposite to their long-term care needs. In particular, caregivers blamed organizations like the AARP and the Alzheimer's Association for failing to address the pressing issue of the affordability of supportive services:

[I]f the Governor doesn't want to step in and [provide respite funding], the state doesn't want to step in and do it, no one wants to do it, then [advocacy organizations] need to have projects to get the monies together for the caregivers. And that has not happened yet. ... I think it's very important that that happens. The caregivers need the money to help with the financing of their loved ones.

Because most caregivers in this study could not obtain long-term care insurance—either due to its prohibitive cost or to pre-existing medical conditions—insurance “solutions” were viewed as a particularly inadequate way of resolving caregivers' financial dilemmas. Asked about his impressions of the AARP, one caregiver's dismissive response was typical of the view that long-term care insurance could do nothing to ameliorate caregivers' immediate need for economic assistance: “They're always advocating long-term care, and long-term care is gone and went.” Indeed, many caregivers described canceling their memberships with the AARP

over for its positions on Medicare prescription drug coverage and its heavy marketing of insurance instruments.

Caregivers viewed the political opportunity structure, then, through the lens of individual efficacy: their capacity to influence decisions about the allocation of public resources depended on effective representation of their interests in policymaking arenas. Unpersuaded by economic or ideological arguments against expanding government long-term care entitlements—and faced with the considerable challenges of financing long-term care for their family members—caregivers entertained far more ambitious expectations for what kinds of policy reforms were possible, given sufficient political pressure on policymakers. While few of the caregivers in this study could be characterized as political radicals (indeed most self-identified as “moderates”) the policy reforms they *expected* were, by the standards of dominant political discourse, “radical” proposals for long-term care reform: they argued for an expansion of Medicaid eligibility to include the working- and middle-classes and government subsidies for in-home care, adult day care, and other supportive services. For these caregivers, the striking divergence between their perceived needs and the “solutions” posed by advocacy organizations was perceived as a failure in organizational representation.

The problem of frame resonance, then, represents a second instance in which the political structures of the “old” welfare state impede efforts to obtain policies that might address newly emergent social needs. The contemporary care needs of families—and caregivers’ expectations for what types of policy reforms might satisfy those needs—are far removed from the range of “politically feasible” programmatic solutions available in policymaking arenas. In a context in which the tenor of debates about managing the costs of existing government entitlement programs has shifted markedly to the right, any significant expansions of state welfare programs

are widely viewed as politically “unthinkable.” For organizational advocates, the terms of contemporary discourse make it virtually impossible to obtain policy solutions that would meet the needs and expectations of their constituents. But without policy goals that resonate with caregivers as meaningful ways of addressing the problems of their everyday lives, caregivers are unlikely to mobilize for policy reforms. In effect, caregivers and their advocates are caught in a vicious cycle: dominant political discourse suppresses the capacity (or willingness) to generate political demand for “radical” changes in public policy, and yet without sufficient political demand, the terms of dominant political discourse—and the range of solutions to long-term care dilemmas—are less likely to change.

#### V. CONCLUSION

Social movement researchers have sought to elaborate the mechanisms by which individuals translate objective political conditions into perceived political opportunities by focusing on the role of organizational actors in shaping the public’s understanding of when and how—and through what means—social conditions may be changed. Activists are portrayed as waiting for signals from the political environment about which types of claims may be efficacious in any given context and then communicating opportunities for action through collective action frames. I have argued that this analytical focus on activists’ perceptions of political conditions conflates *organizational efficacy*—the perception among activists that movement organizations can alter conditions or policies through collective action—with *individual efficacy*—the perception among potential participants that their own contribution in collective action can make a political difference. The slippage between organizational and individual levels of analyses, I have suggested, obscures important differences in the way

activists and potential participants “read” opportunities for political action—and, by extension, how we evaluate the mobilization potential of ordinary citizens.

When both organizational and individual levels of analyses are taken into account in this case, we find that not only do activists and potential participants view the possibilities for long-term care reform differently, but the divergence in these views impedes the ability of potential participants to communicate their demands for state intervention. To feel like they can “make a difference,” caregivers require information about when and how they can participate—they need, in other words, collective action frames and organizational bases for expressing their grievances and acting in pursuit of their interests. For collective action frames to motivate caregivers to participate, they must set forth goals and strategies for achieving policy reforms that are consistent with the needs and experiences of families providing long-term care. But despite a wide range of advocacy organizations working at the state and federal levels, caregivers were largely unaware of—or disillusioned by—organizations pursuing long-term care reform. For the sizable percentage of caregivers who were both interested in and available for collective action, their lack of participation could mainly be attributed to the absence of perceived organizational resources.

The minimal role played by advocacy organizations in the lives of most caregivers in this study—despite the size and influence of many of them—can be explained by the particular challenges of mobilizing for “new” forms of social provision in a welfare state dominated by “old” social policies and political discourses. Social welfare policies designed at a time when long-term care was contained exclusively within the domestic sphere, today impose unique obstacles to identifying and mobilizing family caregivers. Meanwhile, the discursive politics of American welfare state provision have become more divisive over the last decade as

policymakers debate how to manage the increasing costs of existing government commitments. As the balance of power has shifted to the right, market-based solutions to long-term care dilemmas have become increasingly hegemonic in political discourse, and the prospects for expanded government entitlements have dimmed considerably. In this context, advocates who hope to successfully obtain any policy reforms, must modify the scope and ambition of their reform proposals. But in doing so, they leave caregivers who seek a more “radical” restructuring of the long-term care system without the organizational resources to feel like they can make a political difference.

Focusing exclusively on the perspective of organizational advocates, then, can not only produce unduly negative characterizations of the mobilization potential of caregivers, but can mask the ways in which activists’ and constituents’ views about the possibilities for reform may differ. While the final assessment of political efficacy in this case may be the same—caregivers as a whole demonstrated low levels of personal efficacy—it is important to properly diagnose *why* this is the case. Whereas conventional wisdom largely dismisses the capacity of caregivers to mobilize for long-term care policy reform, it appears that in fact many caregivers believe they have the capacity to change the terms and conditions of their everyday lives, but lack the strategic resources to do so. At a time when social policies and political discourse have not yet caught up with the contemporary care needs of American families, the structural constraints on advocacy organizations may limit their capacity to provide those resources for some time to come.

## CHAPTER 6

### CONCLUSION

As modern welfare states debate ways to preserve and restructure existing governmental commitments in the face of intense budget pressures, the issue of how to address newly-emergent social needs is arguably becoming one of the defining issues of contemporary welfare state politics. Commentators have long observed the convergence of several distinct social trends—aging populations, changing household structures and systems of health care provision, and shifting patterns of labor force participation—which together have created a “crisis in care”: demand for care of the young, the old, and the infirm is growing while the supply of private care within the family is substantially contracting (Garey et al. 2002; Harrington 2000; Pierson 2001c). Despite the well-documented effects of contemporary care dilemmas on the economic security of families, the physical and mental health of family care providers, and gender and class equity more generally, American families have demonstrated little inclination for translating their private care problems into political demands for state intervention.

I have argued that the public’s reluctance to view care struggles as public problems stems from the uncertain new terrain in which Americans find themselves: caught between longstanding and deeply-held beliefs about family responsibilities for care on the one hand, and shifting demographic, economic and social realities on the other, Americans have not arrived at any consensus about whether, or to what extent, the state should bear responsibility for care provision. In this dissertation, I have sought to trace how family caregivers navigate between traditional conceptions and new realities of social life, seeking to identify under what conditions

families challenge norms about the private responsibility for family care and reconceptualize care provision as a social responsibility.

Drawing on the concept of oppositional consciousness (Mansbridge and Morris 2001) to more closely examine the multiple dimensions involved in the construction of political demand, I considered four central dilemmas or potential impediments to the development of public demand for state intervention in long-term care provision. First, I explored the challenges of collective identification in a context in which there is no blameworthy opponent, no politically relevant distinction between “us” and “them” but rather an ideology involving longstanding norms about the distribution of public and private resources. Second, I analyzed how individuals develop injustice framings about private, family care provision without recourse to a resonant social rights discourse in the United States that would envision long-term care as a public responsibility. Third, I examined how nonpoor caregivers reconciled their need for Medicaid benefits with longstanding ideological distinctions between “earned” social insurance entitlements for the “deserving” middle class and “handouts” or public assistance benefits for the undeserving poor. Finally, I analyzed the peculiar absence of perceived organizational advocates among caregivers in this study—particularly given the number and influence of aging and other reform organizations in the United States—and the effect of their absence on the willingness of caregivers to communicate their demands for state intervention to policymakers.

Together, these four dimensions of oppositional consciousness—collective identity, injustice framing, ideology, and political efficacy—present a view of American families as balancing deeply-held beliefs about family responsibilities for care against significant care needs that cannot be met through private-sector solutions alone. In what follows, I elaborate two prominent themes in this dissertation regarding the construction of political demand for long-

term care entitlements, and conclude by considering the implications of these findings for the prospects for future public policy reform.

*I. THE HEGEMONIC BELIEF IN FAMILY RESPONSIBILITY FOR CARE*

One of the most striking findings in this study is the remarkable persistence of the belief in family responsibility for care provision—despite its often substantial economic, emotional, and physical costs. This view of long-term care provision as the “natural” and “normal” responsibility of families was hegemonic among the caregivers in this study, shaping the political consciousness of *all* participants, including those who articulated more oppositional interpretations of care provision. The belief in taking care of one’s own, of “handling” the issue within the family, and the fear and guilt of being viewed as a “bad” son or daughter or deficient spouse for seeking help with caring for a loved one, all reinforced an understanding of caregiving as a private and individual, rather than public or social responsibility. So hegemonic was this understanding of care provision, that the possibility of any alternative interpretation—incorporating, for example, a role for the state—did not occur to most caregivers until they faced some disparity between the care they felt obligated to provide and their capacity to satisfy those care obligations.

In tracing the development of an alternative or oppositional understanding of care provision, I have argued that while caregivers *do* adopt understandings of care provision that challenge hegemonic norms about family care provision, these norms do not easily or completely give way in the face of strains on finances, work, family life, and the health of the care provider. Claims for state intervention, in other words, do not emerge whole cloth from crises in care, but are *integrated* with deeply-entrenched beliefs about family responsibility for care provision.

This bridging of private and public understandings of care was seen in the development of three key dimensions of oppositional consciousness: collective identification, injustice framing, and ideological justifications for state intervention.

Because caregiving is generally considered a “natural” extension of family roles, collective identification as a *caregiver* is often not about identifying with a larger group of similarly-situated people, as it is in most cases of political mobilization, but about acknowledging a significant, and emotionally difficult transition in the relationship between the care provider and care receiver. In Chapter 2, I argued that social service providers encouraged this transition by relying on a discourse that marked a distinction between caregivers’ responsibilities as family members and their role as caregivers—characterizing caregiving as work that is above and beyond the “normal” obligations of a partner or adult child. This discursive strategy validated and made visible the efforts of family care providers who genuinely wanted to provide good care for their family members. But it also incorporated a more public understanding of care that challenged longstanding norms about care provision as exclusively a family responsibility. Caregiving discourse portrayed carework as something that can be shared or purchased and it constructed caregivers as an essential component of the American health care system that needs and deserves public support. This deliberate linking of private and public understandings of care provision was essential for caregivers to reconceptualize their family care dilemmas as matters appropriate for public deliberation and collective remediation.

A similar bridging of private and public understandings of care was evident in Chapter 3, in which I examined how caregivers formulated injustice claims against the state. While the discourse of rights has long been used to construct social conditions as unfair or unjust, the United States has a particularly weak tradition of “social rights” to health and economic security.

As a consequence, few caregivers in this study had any specific ideas when they began caregiving about what the government could or ought to do to assist them in long-term care provision. Because the government was not a natural target for the frustrations of families providing long-term care, caregivers frequently blamed themselves for their care dilemmas, viewing unmet care needs as a source of shame or guilt or embarrassment rather than anger or moral indignation. The internalization of blame within the family shifted outward to the state, however, once caregivers developed expectations that the state had a role to play in assisting families. Two sources of such expectations were potentially available to caregivers: a social insurance model of state provision, embodied in the Medicare program, which distributes benefits to all eligible citizens and conceptualizes health care provision as primarily a *state* responsibility, and a need- or income-based model, represented by Medicaid, which views care provision as primarily a *family* responsibility, with the government providing assistance only when the family cannot satisfy basic care needs. Despite the fact that Medicare is the more respected and familiar program for most Americans, and despite their actual ineligibility for means-tested Medicaid benefits, most caregivers drew on the Medicaid program as a source of injustice framing. I argue that the political logic of Medicaid resonated with caregivers because it integrated their need for state assistance in purchasing supportive services with their beliefs in the primacy of family responsibility for care. Thus, even those individuals who challenged dominant cultural understandings of care provision as unjust or unfair retained the hegemonic assumption that care provision is a responsibility of *families first*, insisting that the government should assist families only when all “private” systems fail.

A third instance of this bridging of normative beliefs in family provision of care with the social and economic realities of contemporary care provision was evident in Chapter 4, in which

I examined caregivers' ideological justifications for state intervention. I found that while caregivers were generally more comfortable with a need-based approach to state intervention, their ideological justifications for social welfare provision did not in most cases endorse or reflect the political logic of welfare state residualists, who prefer means-tested programs that offer benefits only for the very poor. In this case, the most acute care crises could be found among the *nonpoor*, as those who qualified for Medicaid received at least some assistance from the state for purchasing supportive services. Thus, while caregivers believed that the government should provide assistance only when families "need" help, they articulated an expansive definition of "need," insisting that the government had a responsibility to protect "middle America" from falling into poverty over circumstances beyond their control. In this sense, caregivers articulated a vision of the welfare state that bridged the means-testing and social insurance approaches to social provision: caregivers' claims for state intervention reflected their beliefs in government assistance for care provision only when families need it, and yet argued for government protection of the middle class from the contemporary risks of long-term care provision.

With respect to each of these dimensions of oppositional consciousness, then, norms and beliefs about family responsibility for care provision played a powerful role in not only legitimating care struggles as something "families do for each other," but also in shaping oppositional understandings of care when they emerged. Caregivers in this case did develop interpretations of their care circumstances that challenged norms about care as exclusively a family responsibility, but the strength of those normative commitments mediated the extent to which caregivers were ultimately willing to shift responsibilities to the state. This duality between the conditions that give rise to, and ultimately constrain, the development of

oppositional consciousness is seen again in discussions of the role of social services and public policies in politicizing caregivers.

*II. THE ROLE OF EXISTING SOCIAL SERVICES AND PUBLIC POLICIES IN SHAPING OPPOSITIONAL CONSCIOUSNESS AND CONSTRAINING MOBILIZATION*

A second theme in this dissertation is the role of existing social services and public policies in both instigating the development of oppositional consciousness among family caregivers and limiting the capacity of caregivers to mobilize for public policy reform. When most caregivers began the experience of providing care to a family member with a chronic disease, they had little accurate information about what care provision would entail or what forms of assistance would be available. Nor did they have any concrete ideas about what kinds of public policies would be useful to them. Contact with social services was typically a crucial turning point in the development of oppositional consciousness among participants in this study.

While most social services lacked an overtly political agenda, sustained exposure to the discourse of caregiving—and the principles of self care and self advocacy—nevertheless had a consciousness-raising effect on caregivers, highlighting similarities in the experiences of family care providers, re-framing individual care problems as collective problems, and emphasizing the underlying structural or socio-cultural factors that make long-term care difficult for families in the United States. Exposure to social services provided caregivers not only with “public” tools to assist them in providing care to their family members, but also concrete examples of what form government benefits might take. California’s Medicaid program offers relatively generous long-term care benefit packages for those who qualify for the program, and stories about these benefits circulated within support groups, classes and workshops, illustrating what caregivers could reasonably expect from the state with regard to care assistance. These expectations formed

the basis of new understandings of citizen “rights” that included not just civil and political rights, but state-funded benefits and services for care provision.

But if existing social services and public benefits programs played an important role in the formulation of new claims to state entitlements, they also limited the capacity of caregivers to mobilize those claims *as political demands* in at least two important ways. First, because the primary source of oppositional interpretations of care provision in this case was Medicaid, a public assistance program in which the government assists only those families who cannot meet their caregiving needs, caregivers’ claims for state intervention tended to connote a sense of failure about their capacity to meet family obligations to care. Thus, caregivers talked about state intervention in terms of *help* or *assistance*, rather than in terms of what the state ought to provide as matter of a positive entitlements or citizen prerogatives. In American political discourse, “needs talk” invokes images of charity and government handouts (Waldron 1996); “rights talk,” by comparison, signifies, as Patricia Williams observed, “the due, the respectful behavior, the collective responsibility properly owed by society to one of its own” (1987, p. 416). By the standards of contemporary political discourse, then, the claims for state intervention forged by existing social services and benefits programs were a weak discursive form of political demandmaking.

Second, if existing social services and public policies provided tools for reinterpreting private care dilemmas as public problems, they also paradoxically limited the willingness of caregivers to *communicate* their claims through political or collective action. In this case, many caregivers were both willing and able to participate in policy reform efforts but lacked the perceived organizational resources to do so. I have argued that existing systems of social provision—and the discursive politics that accompany them—sharply constrain the ability of

advocacy organizations to identify and mobilize caregivers, and to pursue programmatic solutions that would satisfy the care needs of contemporary families. These constraints on organizations not only limit their capacity to demonstrate to policymakers the size and strength of their constituencies, but they restrict their capacity to provide caregivers with a sense that they have the organizational resources with which to influence reform efforts. Without organizations to provide strategic information about when and how they might participate in reform efforts, many caregivers who would have otherwise been willing to engage in policy reform efforts lacked the political efficacy to do so.

Political demand for state entitlements to long-term care, then, is both derived from and constrained by experiences with *existing* social services and public policies. And yet caregivers' claims also bore the imprint of changing social conditions and shifting norms and beliefs about the appropriate role of the state in social welfare provision. I conclude by considering the implications of caregivers' claims for long-term care entitlements for future policy reform efforts.

### *III. THE POSSIBILITIES FOR LONG-TERM CARE POLICY REFORM*

The claims for state intervention that emerged from processes of politicization in this study have distinct implications for contemporary debates about how social policy arrangements should be adapted to address the new social risks of care provision. While the specific content of these claims varied among caregivers—from tax credits to family allowances to state-subsidized home care, adult day care, and nursing home care—it was clear that caregivers with even a minimal oppositional consciousness believed some form of state action was necessary to ameliorate the strains of care provision for contemporary families. But the political context in

which these claims for state entitlements are being formulated poses at least two substantial impediments to mobilization efforts for long-term care policy reform, at least in the near future.

First, the most fundamental obstacle to mobilization efforts for long-term care policy reform is the fact that such efforts are taking place in a time of “permanent austerity” (Pierson 2001a). As a global economic slowdown and demographic shifts toward aging populations put increasing pressure on state budgets, virtually all modern welfare states are currently debating how to modernize their systems of social provision. Mobilization efforts for new or expanded government entitlement programs are thus structurally constrained by the fact that they are taking place against a general backdrop of austerity rather than the expansionary context of the 1950s and 1960s (Pierson 2001c).

Yet while fiscal austerity will likely remain a structural constraint on policymaking for some time to come, how states choose to allocate scarce resources is, as many caregivers themselves argued, a matter of political priorities. In the United States, the tenor of these welfare state debates—and the balance of power—over the last decade has shifted markedly toward neoliberal framings of social problems, and policymakers as a result have made aggressive attempts to shrink governmental commitments to economic and health security. As a consequence, this study observed a striking disparity between the needs—and emergent political claims—of family caregivers and the range of policy solutions deemed “legitimate” by the standards of today’s political discourse. How caregivers’ needs for state assistance are translated by policymakers into programmatic solutions depends in a critical respect on the capacity of advocacy organizations to reconcile the needs of their constituents with these political conditions for policy reform. Advocacy organizations in this case, I have argued, tend to adjust their proposals to accord with dominant political discourse rather than propose more “radical”

solutions that would resonate with the needs of their constituents. The irony of this is that by choosing to pursue policy solutions that resonate with policymakers rather than constituents, advocacy organizations miss a crucial opportunity to mobilize a growing constituency in ways that could potentially transform the very terms of future political discourse.

The emphasis in current political discourse on “privatized” solutions to social welfare problems poses a second obstacle to substantial reform in long-term care policy, as the emergence of market-based solutions to long-term care dilemmas threatens to splinter the constituent base for mobilization efforts. In Chapter 4, I argued that while there was strong cross-class political support for new long-term care entitlements, this support was based more on the need for pragmatic solutions to care dilemmas than on an ideological commitment to public provision. For most families, the turn to the state was an act of last resort. The majority of families went to great lengths to keep the costs of care provision within the family, paying for expensive market-based supportive services out of pocket, drawing down lifetime savings and retirement accounts, and pooling resources among family members. Unlike the market for health insurance for acute care, most caregivers neither held long-term care insurance policies nor viewed them as a realistic possibility due to the high cost of premiums and to medical exclusions. Commentators have observed that because long-term care insurance is a relatively new market, insurers who initially underestimated their potential obligations are currently denying a wide range of long-term care claims, sharply hiking their premiums, and in some cases abandoning the market entirely (Selvin 2006). It is possible, however, that policymakers’ efforts to make such policies more affordable—and reliable—will come to fruition. Already, many more employers are offering group-rate long-term care policies, and from 2000 to 2004, sales of long-term care policies grew by 65 percent (Selvin 2006). Should the accessibility of these

policies improve in coming years, those who can afford market solutions may well drop their support for state intervention, reducing the size of the constituent base for mobilization. As a consequence, those families who are least likely to benefit from private benefits—lower-income families who can neither afford supportive services nor qualify for Medicaid—will face even bleaker prospects for state assistance (cf., Hacker 2002).

While these political constraints pose significant obstacles to long-term care policy reform in the near term, the data from this study suggest reason to be optimistic that political mobilization for such reforms may nevertheless be possible. Even under these rather austere political conditions, this study found ample evidence of a developing oppositional consciousness among family caregivers. Despite strong norms to the contrary, family care providers are beginning to view themselves as members of a larger group or constituency, they are re-envisioning their care circumstances as political grievances, and they are justifying their claims for state intervention with relatively sophisticated ideas about the relationship between care provision and the role of the state in social welfare provision. And, while some family caregivers will always be too overwhelmed by the responsibilities of care provision to participate in social reform efforts, I observed ample evidence that a sizeable constituency of current and former caregivers would be both able and willing to participate in such efforts, if given the opportunity to do so. For an issue that has long been considered a private, family matter, the invocation of the state to help ameliorate the problems of contemporary care provision is a significant development in the political consciousness of the American public. As the ranks of current and former caregivers continue to increase with the aging of the Baby Boomer generation, there is every reason to expect that this burgeoning oppositional consciousness will develop into full-fledged political demand.

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## APPENDIX A

## DESCRIPTIVE STATISTICS OF CAREGIVER SAMPLE\*

	SUPPORT GROUP PARTICIPANTS (N=158)	PEER GROUP PARTICIPANTS (N=80)	INTERVIEW SUBJECTS (N=79)
<b>SEX OF CAREGIVER</b>	N=158	N=80	N=79
FEMALE	104 (66%)	54 (67%)	57 (72%)
MALE	54 (34%)	26 (33%)	22 (28%)
<b>RACE/ETHNICITY</b>	N=156	N=80	N=79
BLACK	24 (15%)	12 (15%)	17 (22%)
HISPANIC	27 (17%)	18 (23%)	9 (11%)
ASIAN/PACIFIC ISLANDER	4 (3%)	4 (5%)	4 (5%)
CAUCASIAN	100 (64%)	46 (57%)	48 (61%)
OTHER	1 (1%)	0 (0%)	1 (1%)
<b>CAREGIVER STATUS</b>	N=158	N=80	N=79
FORMER	17 (11%)	13 (16%)	11 (14%)
CURRENT PRIMARY	98 (62%)	43 (54%)	49 (62%)
CURRENT SECONDARY <sup>90</sup>	43 (27%)	24 (30%)	19 (24%)
<b>RELATIONSHIP TO CARE RECEIVER</b>	N=158	N=80	N=79
SPOUSE OR PARTNER	94 (60%)	47 (59%)	39 (49%)
PARENT	52 (33%)	25 (31%)	36 (46%)
OTHER	12 (8%)	8 (10%)	4 (5%)
<b>EMPLOYMENT STATUS</b>		N=79	N=78
RETIRED OR HOMEMAKER		50 (63%)	39 (50%)
UNEMPLOYED		4 (5%)	9 (12%)
EMPLOYED PART TIME		11 (14%)	9 (12%)
EMPLOYED FULL TIME		12 (15%)	19 (24%)
LEAVE OF ABSENCE		2 (3%)	2 (3%)
<b>MEDIAN AGE</b>			N=78
			63
<b>INCOME</b>			N=75
<\$30,000			18 (24%)
\$31-50,000			17 (23%)
\$51-70,000			11 (15%)
OVER \$70,000			29 (39%)

<sup>90</sup> Caregivers were classified as “secondary” when their care receiver was institutionalized or had full-time hired assistance or if the caregiver identified another family member as being the primary caregiver.

	SUPPORT GROUP PARTICIPANTS (N=158)	PEER GROUP PARTICIPANTS (N=80)	INTERVIEW SUBJECTS (N=79)
POLITICAL IDEOLOGY			N=75
LIBERAL			33 (44%)
MODERATE			21 (28%)
CONSERVATIVE			9 (12%)
OTHER			12 (16%)
PARTY USUALLY VOTES FOR			N=75
DEMOCRAT			54 (72%)
REPUBLICAN			12 (16%)
OTHER			9 (12%)

\*Membership in the three groups was partially, but not entirely, overlapping. Peer group and most interview participants were recruited from support groups. A smaller interview sample of 13 individuals who had never participated in a support group were recruited by social workers. In all, 50 individuals participated in all three groups. For details of this selection process, see methods discussion in Chapter 1.

## APPENDIX B

### ADVOCACY ORGANIZATIONS

To solicit impressions of reform opportunities from advocates who interact with the various administrative agencies, nonprofit organizations, and for-profit care facilities that together constitute the American long-term care “system,” I solicited interviews with organizational founders, leaders, and staff at 20 different local, state, and national advocacy organizations. I defined “advocacy organization” broadly to include any organization seeking to influence public policy and resource allocation decisions within political, economic, and social institutions (cf. McConnell 2004). This definition includes four types of advocacy: (1) *legislative advocacy*, or efforts to influence local, state or federal legislative officials, (2) *administrative advocacy*, or efforts directed at government agencies; (3) *program advocacy*, or efforts directed at changing organizational practices within service organizations (such as nursing homes), or at improving the quality of and access to supportive services; and (4) *legal advocacy*, or efforts to enforce and expand the rights of caregivers through the courts. As the following table of participating organizations illustrates, many organizations specialized in more than one form of advocacy.

## PARTICIPATING ADVOCACY ORGANIZATIONS &amp; INTERVIEW SUBJECTS

Name of Organization	Type of Organization	Name and Position of Interview Subject
Center for Health Care Rights	Administrative Advocacy (Los Angeles)	Aileen Harper, Executive Director
Center for Medicare Advocacy	Administrative & Legal Advocacy (Washington, D.C.)	Alfred Chiplin, D.C. Managing Attorney Toby Edelman, Senior Policy Attorney
Association of California Caregiver Resource Centers	Legislative Advocacy (California)	Vicki Farrell, Chair
Los Angeles Caregiver Resource Center	Administrative & Program Advocacy (California)	Donna Benton, Director
Valley Caregiver Resource Center	Administrative & Program Advocacy (California)	Margery Minney, Director
Redwood Caregiver Resource Center	Administrative & Program Advocacy (California)	Nancy Powers-Stone, Director
Coast Caregiver Resource Center	Administrative & Program Advocacy (California)	Mary Sheridan, Director
Mountain Caregiver Resource Center	Administrative & Program Advocacy (California)	Susanne Rossi, Director
National Committee to Preserve Social Security and Medicare	Legislative Advocacy (Washington, D.C.)	Diane Lifney, Legislative Rep. Alison Bonebrake, Legislative Rep. Sue Ward, Director Grassroots Advocacy
AARP California	Legislative Advocacy (California)	Rigo Saborio, Director of State Management Ernie Powell, Advocacy Rep.
National Alliance for Caregiving	Legislative and Program Advocacy (Washington, D.C.)	Gail Hunt, Executive Director
Bet Tzedek Legal Services	Program Advocacy (Los Angeles)	Janet Morris, Director, Long-Term Care Program Kim Williams, Caregiver Advocate
National Respite Coalition	Legislative Advocacy (Washington, D.C.)	Jill Kagan, Co-Founder
Alzheimer's Association of Los Angeles	Program & Legislative Advocacy	Judith Delaney, Clinical Manager Michelle Barclay, Director, Patient, Family & Training Servs.

Name of Organization	Type of Organization	Name and Position of Interview Subject
Alzheimer's Association (National Office)	Legislative Advocacy (Washington, D.C.)	Stephen McConnell, Senior VP for Public Policy & Advocacy
Family Caregiver Alliance	Program & Legislative Advocacy (California)	Kathleen Kelly, Executive Director
National Center on Caregiving	Legislative and Program Advocacy (California)	Lynn Feinberg, Deputy Director
California Advocates for Nursing Home Reform	Administrative & Legislative Advocacy (California)	Patricia McGinnis, Executive Director Michael Connors, Long-Term Care Advocate
AARP Foundation (Legal Advocacy)	Legal Advocacy (Washington, D.C.)	Stuart Cohen, Director of Legal Advocacy
National Family Caregiver Alliance	Program & Legislative Advocacy (Washington, D.C.)	Susanne Mintz, Co-Founder & President
LA Council on Aging	Administrative & Program Advocacy (Los Angeles)	Ed Woods, President