CARING FOR OUR OWN

Why There Is No Political Demand for New American [redacted]ocial Welfare Rights

S NDRA R. LEVITSKY

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For Greta

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Finishing a book is much harder than starting a book. One arrives at the end with a feeling of accomplishment, but also a profound sense of indebtedness.

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Which brings me to Greta, to whom I dedicate this book. It is impossible to separate Greta's intellectual contributions to this book from the other kinds of life contributions that made this book possible. Greta read every word of this manuscript in all of its versions, from dissertation to book. She engaged me in conversations over dinner and washing dishes that produced some of the best ideas in the book. She demonstrated for me in her own work the power of rigorous scholarship and the importance of pursuing answers to genuinely important questions, and if I ever doubted the caliber or direction of my own research, she showered me with her irrepressible Midwestern optimism. But Greta also gave birth to our baby girl, Esme. There is no single thing that has transformed my life more than that one act. The tedium of writing the final draft of this book was greatly ameliorated by the sounds of baby laughter and Grover imitations, by feeding ducks, making pancakes, riding trikes, and playing in a world where suitcases become boats, pillows become trains, and stuffed animals become family. It is one thing to intellectualize about family beliefs in caring for our own; it is quite another to experience the emotional pull of care provision first hand.

Finally, I want to thank the caregivers, social workers, and activists who gave up their scarce time to participate in this study and who tolerated my quiet observations in their support groups over so many months. All qualitative researchers, I think, hope to do justice to the stories of their participants, and I have made every endeavor to do so in this case. When I made my goodbyes to one support group at the end of this study, a longstanding member of the group joked that he expected me to write something now that would transform the long-term health care system in the United States. We had a good laugh over this, and then an elderly Latina woman, new to the support group, leaned over and whispered to me in all seriousness, "*I really need that.*" This book is really my attempt to figure out why the conversation about long-term care reform has not yet emerged in American political discourse beyond a whisper.

Caring for Our Own

CONTENTS

CHAPTER 1

Introduction

At fifty-nine years old, Susanna did not expect to find herself working full time and caring for both of her ailing parents on her own. Susanna's father and mother have both been diagnosed with Alzheimer's disease and live in a house down the block from her in a lower middle-class suburb outside of Los Angeles. The two children Susanna raised as a single mother are grown and have moved away. Two of her brothers unexpectedly passed away, and her only remaining sibling lives across the country. During the work week, Susanna hires someone to stay with her parents for four hours a day. She cannot afford to hire additional in-home assistance, so her parents are left alone in the afternoon until she returns from work at 5:00 p.m. After work, she cooks them dinner, checks their mail, administers their medications, and does any shopping they require. On the weekends, she is their full-time caregiver—bathing them, dressing them, assisting them with many of the basic activities of daily living. Susanna routinely uses all of her vacation leave caring for her parents, and on at least one occasion required a three-week leave of absence from work. She pays for virtually all of her parents' care on her own. Her parents' modest Social Security and pension checks cover their mortgage and utilities, but little else. Medicare does not cover all of their medications, nor does it pay for their in-home care assistance, and their income is just above the cutoff line to qualify for long-term care assistance under California's Medicaid program. Diagnosed with pre-diabetes, Susanna is concerned that her vision has been getting blurry, but she has not had time to see a doctor. She recently had a root canal, but hasn't had time to pick up her antibiotics. She describes herself as "super stressed" and perpetually exhausted. And yet, reflecting on her circumstances, she observes, "If not me, then who?. . . I look at my parents, and they did everything for me when I was growing up. It's just my turn.

I just never thought I'd do it all alone. I never thought I'd do it both at the same time."

If care provision for society's most vulnerable has historically been understood to be a family responsibility (Harrington 2000), the particular kinds of struggles that Susanna has confronted in caring for her parents—the geographic dispersion of family, the level of care required by her parents, the strains on her income, job, and physical and mental health—are relatively new phenomena. Over the course of the past several decades, the massive entry of women into the paid labor force, changing family structures, and the aging of the population have all produced social welfare needs that are satisfied neither by traditional social arrangements nor by existing social welfare policy.

In the United States, existing social welfare policies were designed for an earlier era, when men served as the primary breadwinners for the family and women provided care for the young, the sick, and the old "for free" in the home (Huber and Stephens 2006). The architects of the American welfare state did not anticipate a world where women participate in the paid labor force at rates equal to or exceeding men,[1] where family forms have been reconfigured, and where changes in health care and living standards have dramatically extended the life expectancy of the average citizen. In 1975, 47% of mothers with children under eighteen participated in the U.S. labor market. By 2009 that number had risen to more than 71%.[2] The percentage of U.S. households headed by a single parent has nearly doubled since 1970.[3] The population aged eighty-five and older—who tend to require very high levels of care—is currently the fastest growing segment of the older population (Folbre and Nelson 2000; Rubin 2001). In 1970, there were just 1.4 million Americans over the age of eighty-five; today it is approximately 6.1 million. By 2050, there are predicted to be as many as 20.9 million baby boomers over the age of eighty-five (Gonyea 2005). The average American couple today has more parents living than children (Smith 1999).[4] Women now spend more years providing care for elderly parents than they do for dependent children (Smith 1999). As a result of these and other trends, contemporary families find themselves struggling with the need for elder care, child care, assistance with single parenthood, and health and economic security (Bonoli 2006).

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[1] During the Great Recession, the number of women in the paid labor market surpassed the number of men for the first time in American history (Rampell 2010).

[2] *BLS Reports*. U.S. Bureau of Labor Statistics. Report 1040, February 2013.

[3] http://www.census.gov/newsroom/releases/archives/families_households/cb07-46.html, retrieved August 6, 2010.

[4] The average American couple has more than two parents living today and typically has fewer than two children (Smith 1999).

One of the most striking characteristics of these social welfare trends is how stubbornly their underlying social arrangements have persisted in the face of changing social conditions. Despite women's dramatically increased participation in the labor market, for example, American women still provide 80% of child care, two-thirds of elder care, and do more than two-thirds of housework (National Alliance for Caregiving and AARP 2009; Williams 2000). Similarly, norms about what it means to be a "good worker"—requiring, in effect, that employees commit themselves full time to their jobs without interruption for childrearing or other family commitments—persist despite increases in both women's labor force participation and parenting commitments from men (Albiston 2005). For most people, these norms represent taken-for-granted expectations for how we should maintain our social welfare. Not only do they remain unchallenged by the public, they remain largely unseen.

Because of the durability of these social practices, values, and norms, many American families find themselves on uncertain new terrain: they continue to hold deep normative commitments to existing social welfare arrangements, even as shifting demographic, economic, and sociopolitical realities have made it difficult for them to live up to these commitments on their own. For years, reform advocates have been calling for new social policies in the United States to offset the risks posed by these long-term trends: flexible work arrangements, paid family leave, tax credits, caregiving stipends, extended school days, state-subsidized home care, respite care, child care, adult day care, and other supportive services.[5] But most reform advocates concede that no matter how striking the social risks posed by new social needs, the United States is unlikely to expand public provision without significant public demand for state intervention (Abel 1990; Daly and Rake 2003; Gornick and Meyers 2003; Harrington 2000; Stone 2000). So where is the "groundswell of public support" (Williams and Boushey 2010:61), the social movement for new social policy which many commentators predicted in the face of these growing unmet needs (Hochschild 1997)? By most accounts, it has never materialized. Even as the economic strains and psychological stresses on families have intensified, the American public has shown little appetite for translating their private family dilemmas into political demands for new social policies (Gornick and Meyers 2003).

For social scientists, this gap between growing unmet social welfare needs and existing social policy presents a rare opportunity to observe the effects of unmet need on the ideology of family responsibility for social

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[5] This literature is far too expansive to cite in its entirety, but a few representative examples include Gornick and Meyers (2003), Williams (2000), Jacobs and Gerson (2004), and Harrington Meyer and Herd (2007).

welfare provision. Theory suggests that if families are unable to provide adequate care for their own, they should reevaluate the taken-for-granted beliefs and values which construct practices such as long-term care or child care as exclusively a family responsibility. *How then does the ideology of family responsibility for social welfare persist even in the face of well-documented unmet need?*

The answer, this book argues, lies in a better understanding of how individuals imagine solutions to the new social welfare problems they confront in their everyday lives. The ideology of family responsibility for care provision is by all accounts the dominant understanding of social welfare provision in the United States. Challenges to that ideology do not simply emerge whole cloth in response to contemporary crises in care, nor does the dominant ideology merely give way in the face of unmet need. The experiences individuals have seeking solutions to unmet needs may highlight the limitations of taken-for-granted social rules and practices, and in some cases, suggest the possibility of alternative social arrangements. Existing social services and social welfare policies in this regard provide key resources for imagining alternative social arrangements for care. But discontent with unmet needs and awareness of alternative social arrangements do not alone produce demands for new social policy. The political imagination requires a way of integrating new solutions to unmet needs with more familiar ways of thinking and talking about social welfare provision. This synthesis, referred to here as *discursive integration,*[6] produces new understandings of social welfare provision but rarely does it displace the belief in the family as the primary guarantor of health security. Understanding the role of existing social welfare policies in the process of grievance construction as it relates to both facilitating and obstructing the development of oppositional understandings of care provision is critical to seeing how Americans reproduce the dominant ideology of family responsibility even in the face of unmet need.

IDEOLOGY OF FAMILY RESPONSIBILITY

The ideology of family responsibility, sometimes referred to as the ideology of "familism" or "familialism" (Barrett and McIntosh 1982; Dalley 1988),

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[6] In earlier work (2008), I referred to this concept as *discursive assimilation*. My colleague Howard Kimeldorf observed that assimilation almost always suggests that the new is being assimilated into the old, or that the old has the power to absorb, neutralize or co-opt the new. This downplays the possibilities of oppositional understandings emerging from the combination of the old and the new. Given the evidence of counterhegemonic understandings of care provision that emerged in this study, I have since changed the term to *discursive integration*.

refers to a particular set of norms and beliefs about who should be responsible for the care of society's dependent members. Ideology is conceived here not as a single all-encompassing schema that determines how people think and act, but as a process by which meaning is constructed, reinforced, and in some cases transformed (Ewick and Silbey 1999). In this view, ideology shapes social life not by controlling people's thoughts, but by being utilized as a form of sense making. For ideology to be reproduced, it has to be "lived, worked out, and worked on. It has be invoked and applied and challenged" (Ewick and Silbey 1999:1037). Thus, when adult children care for their aging parents as a way of reciprocating the care that they received growing up, they reproduce the ideology of family responsibility (Ungerson 1987). When a daughter takes care of her mother the way her mother cared for her grandmother, she reproduces the ideology of family responsibility. The ideology of family responsibility is constituted by social norms portraying the family as a cohesive unit based on mutual responsibility and affection (Dalley 1988) where women should—and do—carry most of the burden and cost of caring. Caring for family members is understood as a natural or inherent moral obligation, superior to any other form of care, such as paid home health care or institutional care.

Norms about the "naturalness" of family responsibility for care are so pervasive in western societies that it's very hard for people to imagine the social organization of care in any other way. Asked to explain why they are caring for their relatives, many people will simply make reference to their family relationship (e.g., "I'm her daughter." or "He's my husband.") and see no need for explanation or elaboration (Walker 1991). So powerful are these normative beliefs in the obligation to care for family, that even adult children who feel they owe no debt to their parents—who, for example, grew up abused by a violent or alcoholic parent—nevertheless still feel an obligation to provide care, or express guilt if they fail to do so (Abel 1991; Walker 1991).

The belief that family should bear the primary burden of care provision has two corollaries in public policy (Montgomery 1999). First, the government should provide public services and benefits only in cases where there is no family or after family resources have been exhausted. In other words, state resources should not be provided for people who "ought" to be relying on support from their families (Finch 1989). Second, only the minimal amount of support should be provided in order to reinforce—and avoid weakening—family-based care.

Social scientists and historians have amassed wide-ranging empirical evidence that family care patterns are not, in fact, a reflection of an inherent or natural moral imperative. The "naturalness" of family care, for example, is undermined by the reality that some people do not provide care for their relatives (Finch 1989). Indeed there are many laws that are designed to coerce families to take on their "natural" responsibilities. The consistency and patterning of family care suggests not a biological imperative, but a coherent ideology underlying these practices (Dalley 1988). Feelings of "duty," "obligation," and "responsibility" are not natural feelings; they are prescriptive concepts, rooted in a particular view of the moral order of the social world (Finch 1989)

Historically, care has been provided both in and out of the household, as unpaid family labor or as paid labor in the market. Janet Finch's (1989) review of historical evidence on family care provision finds that in the early industrial period, for example, when conditions of poverty were especially harsh, family relationships were highly utilitarian; relatives offered support only if there was a possibility of mutual benefit. Anything short of that would have been considered an unaffordable luxury. Hendrik Hartog's 2012 study of inheritance and old age from the mid-nineteenth to the mid-twentieth century reinforces this. Contrary to the view of family as naturally fulfilling their obligations to family, Hartog finds that inheritance was routinely used by older people as an inducement to persuade—or coerce—family or others to care for them in old age.

The particular balance of state and family care has varied across time and place, reflecting not just a society's beliefs, but also its political system, economic structure, and cultural practices. That balance is often reflected in and reinforced by the laws and policies of that society (Finch 1989; Glenn 2010; Montgomery 1999; Walker 1991). In the United States, contemporary care practices have been shaped by a long line of legal policies—dating back to English Poor Laws in the sixteenth century—legitimizing and reinforcing the primacy of family responsibility. Recognizing that a sense of family obligation does not develop in a vacuum and that families do not always fulfill their natural obligations towards each other, British policymakers enacted legislation to ensure that people do not abandon their responsibilities to care for family (Finch 1989). Today, twenty-two states in the United States retain filial responsibility laws on the books, which designate certain family members as responsible for the care of older parents and effectively coerce them into assuming their "proper" responsibilities (Montgomery 1999). The state has also sought to encourage families to care for their relatives through incentives, such as tax allowances for those caring for dependents.

But law and social policy have most powerfully influenced the reproduction of the ideology of family responsibility through their capacity to grant and withhold services and subsidies. As Alan Walker (1991) has observed, the influence of social policy on family care provision lies in the assumptions it makes about the nature and availability of family assistance in rationing