CARE JUSTICE

Reframing Public Policy, Elevating Care Work

AGING AND SOCIETY

NANCY R. HOOYMAN

ROUTLEDGE

"This comprehensive and thought-provoking book, offers new ways of thinking about family caregivers and direct care workers, and their interdependence in providing essential home- and community-based care for older adults. Nancy Hooyman lays out promising and meaningful strategies to promote positive social change and achieve care justice in our country. It is time to respect and address both unpaid and paid care work for older adults in the U.S. and get this right."

Lynn Friss Feinberg, *Former Senior Strategic Policy Advisor, AARP Public Policy Institute*

"Nancy Hooyman offers an engaging analysis of the profound consequences of society's undervaluing of the essential work of elder care for both unpaid family caregivers and underpaid home care workers. By providing a window into the realities faced by women and persons of color who often bear the strain of devalued care, she illuminates how structural inequities by gender, race, social class, citizenship, and sexual orientation often shape their daily lives. In addition to highlighting the systemic problems underlying the devaluing, Hooyman offers readers the opportunity to explore transformational solutions and envision a society which adopts a care justice paradigm. *Care Justice* is an essential resource for students, scholars, activists, and policymakers who believe we have a collective responsibility to elevate and credit care work."

Judith G. Gonyea, *Professor of Social Work, Boston University, USA*

"In this book, Dr. Nancy Hooyman persuasively argues for social policy transformations that increase support and enhance the value of caregivers in unpaid and underpaid positions. With the rise in both numbers of older adults and the complexity of caregiving needs, Dr. Hooyman provides an insightful and well-researched discourse with the intent to stimulate changes in approaches to home and community care. The six core components of care justice are fundamental to reducing inequalities faced by unpaid and underpaid care providers. As I read the book, I was reminded of the late Rosalynn Carter, herself an advocate for caregiving reform, who famously stated that "there are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers." Care provision is a ubiquitous role and I hope that we take up Dr. Hooyman's invitation to envision a society that values the essential work of care."

Nancy P. Kropf, *Kenneth D. Lewis Distinguished Chair in Interdisciplinary Health Studies and Professor at the Byrdine F. Lewis College of Nursing and Health Professions, Georgia State University, USA*

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Care Justice

This book develops a care justice framework to critique and disrupt current policies and reframe a policy blueprint for elevating a just organization of care for unpaid family caregivers and underpaid home care workers assisting older adults. In doing so, Hooyman invites readers to envision a society that fully values the essential work of care.

The book is distinctive in its analysis of the interrelationships among both types of care laborers, who often face structural constraints on their decision to care and whose work is devalued and marginalized. Their care work affects every member of society, but it is generally invisible to others, and its economic value is rarely recognized by policymakers. How care work is organized and unrewarded typically has the most financial, physical, and emotional costs for women, people of color, and immigrants across the life course. Inequities for care workers by race, immigrant status, class, and sexual orientation are rooted in systemic racism, sexism, classism, xenophobia, and homophobia. In this book, policy priorities and change strategies are reframed to attain the six core components of a care justice framework, which include fundamental structural changes to elevate care work, ensure meaningful choice to care, and reduce systemic inequities faced by care workers. This framework is informed by feminism, Black feminism, intersectionality, and care theory. By conceptualizing care justice, the author aims to stimulate new discourse and action related to the care of older adults – the most important work in society – and make the seemingly unattainable attainable.

This timely book will be salient to anyone committed to diversity, equity, and inclusion and with an interest in policy, gerontology, disability studies, ethnic studies, feminist studies, social justice, social work, and social welfare.

Nancy R. Hooyman is the Hooyman Professor of Gerontology and Dean Emeritus in the School of Social Work at the University of Washington, Seattle, USA. Her scholarship explores gerontological and women's issues, including multigenerational policy and practice, gender inequities in family caregiving, feminist gerontology, loss and grief, and gerontological curricular change. She is co-author of the influential textbooks *Living Through Loss: Interventions Across the Life Span* (2nd edition, 2021); *Social Gerontology: A Multidisciplinary Perspective* (10th edition, 2017); *Aging Matters: An Introduction to Social Gerontology* (2014); *Feminist Perspectives on Family Care: Policies for Gender Justice* (1995); and *Taking Care of Aging Family Members: A Practical Guide* (1993). She is a member of the American Academy of Social Work and Social Welfare and a recipient of lifetime achievement awards from the Association for Gerontology Education in Social Work Education, the Council on Social Work Education, and the Gerontological Society of America.

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Nancy R. Hooyman

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Preface

My experience as a long-distance caregiver for my mother dying of cancer, long before palliative care and hospice existed, inspired me to enter the field of gerontological social work in the 1970s. After observing the sexism and ageism in how health care providers treated my mother, I was motivated to conduct research on family caregiving and to prepare social workers with the competencies needed to respectfully work with older women and their caregivers. At that time, caregivers were relatively invisible, and the term was not even part of our professional or personal lexicon. I recall approaching a large Seattle corporation in 1984 to discuss their including caregiving support in their employee assistance program, only to be told that they did not have any employees who were caring for elders. My research in the 1980s, with Dr. Judith Gonyea and MSW students, was the first to measure objective and subjective burden and heightened my awareness of family caregivers' heavy demands and impossible choices. However, like many caregiving scholars at that time, drawing upon C. Wright Mills' typology, I viewed caregiving as a personal trouble to be addressed through individual solutions such as increased education for families, not as a public issue requiring systemic change. I recognized it as a woman's issue but not a feminist issue. My early practice-oriented book *Taking care: Supporting older people and their families* (with Wendy Lustbader) largely focused on individual practice strategies to enhance families' effectiveness in their care, with minimal attention given to changes in systems and policies to value caregivers.

My awareness of structural inequities facing family caregivers grew in the 1990s and early in the 21st century, when my scholarship focused on gender inequalities in care and conceptualized long-term care as a feminist gerontological issue. In the 1990s, *Feminist perspectives on family care (*with Judith Gonyea) addressed the need for policy changes to support family caregivers. However, I failed to consider how care is both feminized and racialized, and only briefly examined the essential role of home care workers and their interdependence with family caregivers. In fact, it was not until my participation in the national Eldercare Workforce Alliance (EWA) in the early 2000s that I explicitly recognized the racial, class, gender, and citizenship inequities faced by home care workers. I also had opportunities to learn from and collaborate with EWA members in nursing and PHI staff, including then Executive Director, Steve Dawson, regarding the feasibility of the advanced care role for home care workers. In conducting focus groups with both nurses and social workers, I was struck by how professional turf issues contribute to the invisibility of underpaid care workers. I later collaborated with Ai-Jen Poo and her Domestic Workers Alliance staff as part of a Kitchen Cabinet for Caregiving on models and financing of long-term care. Through these national policy advocacy experiences,

I grew in my knowledge and understanding of inequities faced by direct care workers rooted in systemic racism, sexism, classism, and heterosexism, and xenophobia, the imperative for fundamental structural change, and the potential for increased government responsibility.

Five years ago, Dean Birkenkamp, Routledge publisher, and Carroll Estes, editor of their *Aging in Society* series, approached me about writing a book for this series. Although I was immersed in finishing the second edition of *Living through Loss* (with Sara Sanders and Betty Kramer), this unexpected invitation provided me with an opportunity to write a book that I had been imagining for several years. I want to acknowledge Dr. Karen Fredriksen-Goldsen, who organized a symposium on care justice at the University of Washington in honor of my 2019 retirement. This event motivated me to conceptualize a care justice framework to reframe policies to elevate the essential work of care and reduce inequities faced by both unpaid and underpaid care workers. It has also been an opportunity to draw not only on feminist theory but also Black feminist, critical race feminist, and intersectionality theories in proposing core components of a care justice framework.

When I started working on this book in 2021, I did not realize what a daunting undertaking it would be to conceptualize a new framework for change and draw upon a wide range of policies and theoretical perspectives, including care theory and the ethics of care salient to care work. In many ways, the care justice framework is not and never will be complete. Instead, it will continue to evolve as students, scholars, policy advocates, and community activists assess its relevance to their work. And as is the case with any book that addresses policies and relies on survey data, it will already be somewhat out of date by publication. Nevertheless, I hope that this conceptualization of care justice challenges you to develop new ways of thinking and acting related to care labor and to engage in the public discourse, scholarship, and advocacy needed to reframe public attitudes, cultural mindsets, and policies toward a just organization of care.

Drawing upon critical race and feminist theories and attempting to take account of the intersecting identities of care workers, I have chosen to use the term Latinx, which is an alternative to the gender binary inherent to formulations, such as Latina/o, and is used as a gender-neutral term by and for anyone of Latin American descent who does not identify as either male or female. Although the use of Latinx has been widely debated and is not used by many Latinos or Latinas, it reflects my commitment to queer subjectivity. I also recognize that preferences for terminology by race, ethnicity, nationality and gender identity will continue to evolve. I will view this book to be "successful" if its concepts and discourse generate reflection and debate, activism and analysis, and policy and political change relevant to attaining care justice for unpaid and underpaid care workers.

Nancy Hooyman, April 2024

Acknowledgments

I greatly appreciate the support of colleagues who encouraged me to write this book, particularly Dr. Clara Berridge and Dr. Judith Gonyea, who were sounding boards in my early formulations of the content, and Dr. Karen Fredriksen-Goldsen, who organized a national symposium on care justice to honor my career during a legacy retirement event. This symposium motivated me to conceptualize a care justice framework both for this book and for the Donald P. Kent Award lecture at the Gerontological Society of America. I especially thank Dr. Carroll Estes, series editor of the Routledge Series on Aging, and Society and Dean Birkenkamp, Senior Editor | Sociology at Taylor and Frances, who asked me "what would I like to write about?" and patiently waited for me to frame the book – and even more patiently for me to finish it – during a process lengthier than any of us initially anticipated. During this multi-year process, Carroll and Dean, along with Nicholas DiCarlo, Assistant Editor of the Series on Aging, were supportive through their responsive and critical feedback. We were a team determined to finish this project, despite setbacks with co-authorship. Kath Wilham, a skillful editor, was central at the copy editing and index phases. Natalie Turner, a doctoral student in social welfare at the University of Washington School of Social Work, was pivotal by assisting with literature searches and offering critical insights on early drafts.. Through her policy-focused doctoral work, she represents the next generation of scholars contributing to care justice. Last, I am deeply appreciative of the candid and wise feedback from Dr. Kezia Scales, Vice President of Research & Evaluation, PHI who profoundly contributed to my understanding of the daily inequities faced by care workers.

1 Why Care Justice?

Overview

This book is about the work that makes other work possible: the essential work of elder care by unpaid family caregivers and underpaid home care workers (Poo, 2015). It is about the inherent value of the care of older adults with chronic illness or disability living in their homes, which benefits older adults, their families, and society. Social location shapes the division and nature of caring labor; the experience of care varies with who is providing the care, how, where, and under what conditions. This book highlights how structural inequities by race, gender, sexual orientation, social class, and citizenship status affect how care is experienced by families and home care workers. Central to their experience is their essential labor is unpaid or low wage, reflecting its societal devaluation. Care labor is undervalued in part because it is viewed as unskilled; this misperception perpetuates a social organization of care that marginalizes and often renders invisible and less worthy those who typically provide care – women, people of color and immigrants. To value and elevate care, a care justice framework and its core components are posited. This conceptualization is intended to contribute to public discourse about the need for care justice and to scholarship and advocacy to attain it as well as new ways of thinking and acting related to care labor and the economy of care.

I invite you to join me in envisioning a society that fully values and elevates the essential work of care and reduces structural inequities faced by care workers. This chapter sets forth a rationale for focusing on both family caregivers and home care workers. Both types of care workers are interdependent, undervalued, and facing structural inequities, which further this devaluation and make the case for a just organization of care. After defining care justice, the core components of a care justice framework are identified. Attaining these components would be transformational in how care is structured and valued. Feminism, Black feminism, critical race feminism, intersectionality, social justice, care theory, and an ethic of care inform this framework for change, but also differ from a conceptualization of care justice.

Who provides most long-term supports to older adults?

Unpaid family caregivers

Approximately 38 million family members care for older relatives (Horovitz, 2023). They are unpaid carers because they typically do not receive financial compensation, although in some states, family caregivers are paid a modest wage through Medicaid-funded consumer-directed care or receive a care stipend. This compensation is the exception, not

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the norm, since policies often assume that families – particularly women – should provide care out of love, compassion, or duty.

Because of demographic and societal changes, a gap exists between older adults' need for care and the number of available family caregivers (Edwards, 2021; Glenn, 2010). Family caregivers have received more attention in the media, policy, research, and development of practice interventions than underpaid care workers have. Nevertheless, family caregivers often feel alone, isolated, and without adequate supports, especially when supportive services were constrained during the coronavirus pandemic.

Underpaid home care workers

Although unpaid family caregivers provide most personal assistance for older adults, over 2.8 million underpaid home care workers give more paid support than any other segment of the home and community-based services (HCBS) workforce, providing person-centered care in the home and community. They are the central pillar of this sector of long-term services and support (LTSS) (PHI, 2023a, 2023d, Scales, 2019a). *Home care worker* describes collectively direct care workers who are home health aides (HCAs) and personal care aides (PCAs). They spend more in-person time with long-term care consumers in their homes and other noninstitutional residential settings than other health or social service workers (Drake, 2020; Scales, 2020a, 2020b).

The pandemic made visible that those who provide LTSS are essential workers and unsung heroes, who nevertheless lacked adequate protections and supports. Although workers' courage and selflessness were praised, this did little to reduce the risks that underpaid care workers – disproportionately Black, Brown, and female – faced or offered safety, training, or higher wages. Unfortunately, the increased visibility of home care workers during the pandemic has largely faded. Many who left the workforce because of COVID-19 have not returned, and recruiting new workers for poorly paid jobs has become more difficult with an increased cost-of-living. As with family caregiving, the resultant shortage of home care workers contributes to a care gap between those needing home care and the underpaid workforce to provide it.

I frequently use the term care labor in lieu of paid and unpaid care because caring for others is typically extremely hard work, often against immeasurable odds (Cranford, 2020; Folbre, Howes & Leana, 2012; Glenn, 2010). Those who care, however, may not view care as labor, since caring also entails interdependency, reciprocity, compassion, gratitude, and love. Similarly, when caregiving is paid (albeit poorly), it does not render it uncaring or solely instrumental. Instead, paid care in the marketplace may sometimes be superior to unpaid care within excessively burdened families.

Care of older adults in home and community-based settings

Care of older adults with chronic illness or disabilities

As a gerontologist, my priority is addressing the care needs of the rapidly increasing number of older adults with chronic illness or disability, many of whom are women, people of color, childless, and living alone. Gerontologists have long emphasized that the older population is the most heterogeneous of any age group, given their varied life experiences across the life course and into old age (Dannefer, 2021). What is salient to a care justice framework is their increasing diversity by race/ethnicity, sexual orientation/

gender identity, and socioeconomic status. When combined with an inadequate supply of care workers, a critical policy question is how to meet the growing care needs of a diverse aging population without further exacerbating systemic inequities faced by unpaid and underpaid care workers.

Both feminist scholars and gerontologists point to the importance of relationships between those who provide care and those who receive it (Berridge, 2012; England, 2005). In focusing on the interdependence between family caregivers and home care workers, I do not mean to overlook or minimize such relationality with older adults. In a care justice framework, gains for care workers do not occur at the expense of those receiving care, nor do gains for older adults occur at the expense of those caring for them. However, a detailed examination of older adults' perspectives on receiving care is beyond this book's scope. Nevertheless, because of the mutuality of relationships between those receiving and giving care, I avoid the term care "recipient," which can imply elders' passivity (e.g., being acted upon) and minimize the reciprocity in care relationships. I also aim to avoid the terms patient or client, which can objectify or medicalize an older person. If I do use those terms in summarizing research findings, I hope the reader recognizes that the person receiving care still have agency, autonomy, and reciprocity with care workers. Such relationality is central to care justice.

The role of ageism and ableism in the devaluation of care

This interdependence is also reflected in how the low status and pay of those providing care are linked to the devalued status of those receiving it; in other words, structural inequities due to ageism and ableism that negatively affect older adults are interconnected with the devalued status of those who care for them (Berridge, 2012). Ageist and ableist narratives and policies stigmatize both members of the care dyad, with the fight for better working conditions and pay for care workers inseparable from improving conditions for those receiving care (Gould, Sawo, & Banerjee, 2021). Greater policy attention, however, has historically been given to preventing risks to older adults' well-being than to protecting the well-being of those caring for them (Keating, McGregor, & Yeandle, 2021). A care justice framework takes account of the complexities of interdependence among older adults, home care workers, and family caregivers.

Home and community-based care

This book focuses on home and community-based care, specifically in private homes, rather than hospitals or skilled nursing facilities. This is because most older adults prefer to age in place, and most unpaid and poorly paid care is provided in the privacy of the home. Federal policy, although not necessarily funding, also prioritizes care in HCBS. The limitations of HCBS, however, are often determining factors in whether older people can remain in their homes as they age. Positive changes in Medicaid, albeit still limited, have increased the number of older adults receiving HCBS, as discussed in Chapter 2.

In addition to community-based care, the devaluation of care work and the need for care justice are embedded in a larger set of structural factors in settings such as skilled nursing and assisted living facilities and hospitals, and among those who care for children, younger adults, and persons living with disabilities and chronic mental illness. All types of care labor, such as childcare and teaching, are undervalued in American

society. The care justice framework components are to some extent implicit within the disability justice movement, which is a source of pride, community, and rich culture of relationship-building and innovation and is committed to cross-movement organizing (Berridge, Ganti, Taylor, Rain, & Bahl, 2022; Piepzna-Samarasinha, 2018). While this book focuses on caring for older adults, there are similarities in care work to meet critical needs with other populations, especially those living with disabilities, from which we can learn.

Why focus on policy?

With care embedded in a network of relations in society, there is a continuous intersection between care arrangements and public policy, as described by the feminist scholar Daly (2001). Feminists contend that all policy is personal in terms of how it affects those giving and receiving care. Rather than viewing care as a personal trouble requiring individual solutions, care work is a public issue requiring structural change (Aronowitz, 2012)). This book focuses on policy and its implementation through programs, since policy is central to constructing care work by promoting certain forms of care and norms about who should care, how, and where. Moreover, policy – whether intentionally or unintentionally – contributes to and maintains inequities. Care of older adults in the public discourse is largely socially constructed as a private family concern and as women's work. Because of this framing, policy shapes care workers' low status, devaluation, inequities, and costs.

Interdependence of unpaid and underpaid care workers

Other books on care have addressed the needs of paid care workers *or* family caregivers, but relatively few explicitly speak to both. The shared strengths and inequities faced by both types of care workers are made visible throughout this book. I address both because their care experiences and their costs are often similar and interconnected. Most importantly, the interdependence of family caregivers and home care workers, a core component of care justice, is vital to LTSS, as captured by James Murtha, MSW, a disability advocate:

> *If family caregivers are the backbone of the long-term services and supports system – with appropriate support, connections and resources, paid caregivers are the connective tissue that keeps the backbone of the system together.*
>
> (Administration for Community Living (ACL), 2021, p. 60)

Both families and home care workers enhance older adults' quality of life by keeping them safe at home; they also reduce health care expenditures from falls, emergency room visits, hospitalizations, and skilled nursing home care (Bandini, Rollison, Feistel, Whitaker, Bialas, & Etchegaray, 2021; Reckrey, Federman, Bollens-Lund, Morrison, & Ornstein, 2020). Paid and unpaid care laborers work in relation to providing care, so that the boundaries between labor and love as experienced by both are often overlapping (Duffy, Armenia & Stacey, 2015). Some family caregivers are also underpaid care workers, if they are part of the home care workforce or paid as independent providers. Others enter the home care job market after caring for relatives. A division between the provision of direct and indirect care is indistinct, since most home care workers, like family

caregivers, provide indirect care by assisting with daily tasks as well as direct, hands-on, and emotionally engaged care (Anderson & Hughes, 2015).

Predominance of women among both unpaid and underpaid care workers

Although an increasing number of men provide care, both the providers and receivers of care in old age are primarily women, making LTSS a feminist gerontological issue. Moreover, women of color predominate among home care workers, rendering LTSS an issue for Black and critical race feminists. Gerontologists, however, have addressed care and its related inequities by gender, race, class, and citizenship status less than care theorists, disability scholars, and activists, which suggests an under theorization of care in aging (Berridge, 2012; Dannefer, Stein, Siders, & Patterson, 2008). This book draws upon analyses of care labor by feminist and Black feminist scholars and advocates, although both have given greater attention to unpaid family care than to underpaid care.

Devaluation of both unpaid and underpaid care workers

Both are devalued, largely because of the low status of their feminized and racialized care work. Both often have little choice about whether and how to provide care because of racism, sexism, classism, xenophobia, or homophobia that constrained their educational and employment opportunities. Both experience care relationships characterized by power asymmetries, low status, and the struggle for identity, agency, and dignity in systems that deny them (Berridge, 2012). Dependency is inherent in the status of unpaid or underpaid care laborers; those with more power – policymakers, employers, other family members, and medical providers – often make decisions about the conditions of care that negatively affect them. According to the feminist scholar Kittay (1999), the affective attachments and relational identity that derive from intimate care become a subordinate status in the social and political context, furthering the invisibility of home and family care. While the current unjust organization of care often results in devaluation of care, devaluation underlies the unjust organization of care; the two constructs are so intertwined that they are difficult to disentangle.

Costs of care and precarity

Despite women's gains in the paid workforce in the past 60 years, care as a female-identified activity persists (England, P., 2005; Folbre, 2002), contributing to the societal devaluing and structural inequities of care labor. Since the value of care labor is rarely recognized or adequately supported, there is typically low or no pay and limited benefits, often leaving both families and home care workers in economically precarious positions. As noted by the feminist scholar Folbre (2002), capitalist markets tend to penalize individuals who engage in caring activities, which undermines the very practices they depend on for their existence. For example, when women and people of color move out of the paid workforce to care for others at home, they typically receive no compensation for their care work and earn less than men and non-Hispanic whites when they later re-enter the labor market. Gender and racial inequities in underpaid care work negatively affect financial security and physical and emotional well-being across the life course and particularly in old age. Moreover, the devaluation of care is exacerbated by onerous work conditions that directly affect a worker's access to their own future care and

well-being (Berridge, 2012). This marginalization of women and people of color across the life course reflects the systemic undervaluation of the essential work of care (Keating, McGregor, & Yeandle, 2021). The feminist scholar Lake (2023) contends that society cannot be considered to be just if women bear the overwhelming burden of responding to human need, and if Black and Brown women bear a disproportionate burden of performing undervalued care labor, often for dominant others.

Precarity – feeling uncertain, insecure, and/or vulnerable in one or more domains of life – is another consequence of the devaluation of care. It is central to understanding how cumulative effects from care-related inequities earlier in life amplify disparity in later life for historically marginalized care providers (Crystal, Shea, & Reyes, 2017; Grenier, 2020; Grenier, Lloyd, & Phillipson, 2017). Cumulative disadvantage describes a process of increasing socioeconomic and health inequality over the life course, which is salient to understanding care workers' experiences of financial insecurity (Dannefer, 2021). The concept of precarity has generally been applied to the risks and insecurities of older adults, especially those who are low-income and Medicaid-eligible and who lack adequate social and economic supports Grenier, Phillipson, & Settersten, 2020). However, it is also salient to those who care for older adults because the devaluation of care results in uncertain and financially insecure work and economic strain, intensifying inequality in old age.

I turn now to defining care justice and its core components to guide reframing of policies. To clarify, I am presenting a *framework* rather than a *theory* of care justice. Indeed, this framework is aspirational – a way of conceptualizing what distinguishes a society characterized by care justice. Recognizing that there is nothing inevitable or permanent in how care is organized, the reframing of care work is envisioned in Chapter 7.

Care justice framework

Definition of care justice

Care is conducted in the context of individual relationships, but shaped by historical, political, economic, and social forces, which marginalize and devalue those who provide care – predominantly women and people of color. However, in my conceptualization of care justice, care is universal, skilled, and valued labor essential to individual and societal well-being. Relationships, reciprocity, and interdependence among those who provide and those who receive care are highly valued and rewarded. Systemic and deeply rooted inequities by race, gender, citizenship status, sexual orientation, and social class, which have oppressed care workers and adversely affected their well-being and quality of care, are markedly reduced. Care workers have a choice in whether and how to care for those who need it and to have their choice supported without judgment.

To elevate the work of care, fundamental systemic changes to the policies, programs and practices that structure care occur. Such structural changes take account of the intersection of multiple identities to reduce systemic inequities due to sexism, racism, classism, xenophobia, and homophobia and thus the marginalization of those who provide care. The reframing of policies and programs ensures that care is a sustainable collective public responsibility where those who need care receive adequate assistance and those who provide care have voice, agency, and meaningful options. Women and Black and Brown people no longer bear the burden of devalued care but are able to be and do what they value, congruent with care theory (Engster, 2007, 2014; Engster & Metz, 2013). Care

arrangements are sustainable when they take account of the standpoint of the people who give care and ensure equitable access to economic resources and supportive social connections for them. Care justice builds upon but differs from theories of social justice, care theory and ethics of care.

Emancipatory gerontology

A care justice framework is congruent with *emancipatory gerontology*, a theme of the Routledge series on *Aging and Society*, but also differs (Estes & DiCarlo, 2019). Both care justice and emancipatory gerontology explicitly address structural power differentials inherent to oppression that create and maintain inequities for marginalized groups and individuals. Similarly, care justice emphasizes the imperative for fundamental change in policies and institutions that currently limit choice, dignity, and equity for unpaid and underpaid providers of care. Both frameworks address precarity due to underlying social inequities and roots of oppression, although emancipatory gerontology gives greater attention to the trauma of precarity and the psychological experiences of being devalued and exploited (Estes, Yeh, & DiCarlo, 2021).

Emancipatory gerontology forefronts public knowledge of the individual and social consequences of major policies and institutions in relation to aging and to generations across the life course, which encourages activist-scholar approaches to research, policy, and practice. With its focus on inequities within and across generations, emancipatory gerontology gives greater attention to embattled reproductive rights and resultant mental and physical hardships for women than does care justice, with its priority on care for older adults (Estes, DiCarlo, & Yeh, 2023). Care justice brings a life-course perspective to understanding inequities faced by care workers but does not explicitly address developmental issues earlier in the life span among children and young adults that characterize emancipatory gerontology. By advancing the perspective of public goods, emancipatory gerontology scholarship, similar to care justice, can alter how we think about the labor of family support, care services, and women's work in the care economy. Emancipatory gerontology proposes "epic theory" (Wolin, 1969) or to "take it big" (Aronowitz, 2012) through policy interventions (Estes, DiCarlo, & Yeh, 2023). A care justice framework explicitly draws upon feminist, Black feminist, and care theories to inform the core components that reframe policies to advance care justice, but it does not attempt to join a grand theory to action.

Although emancipatory gerontology and care justice frameworks share commonalities, I contend that care justice is best suited to advance collective responsibility for a just organization of care that elevates and rewards essential care labor explicitly for older adults and to reduce inequities faced specifically by family caregivers and home care workers who assist them.

Core components of a care justice conceptual framework

The six core components or defining characteristics of this framework are:

1 *Care work is universal and skilled labor essential to individual and societal well-being. Care is a public good with economic and social value.*
2 *The relational nature of care work, with its interdependence and reciprocity, is valued and supported.*

3 *Economic, political, and social structures empower men and women to be able to choose whether and how to care for those who need it – and to support their choice without judgment.*
4 *Society invests in care as a public good and infrastructure where care labor is equitably organized, accessible and sustainable.*
   a *Those who provide unpaid care are valued with financial compensation to reduce care's economic costs.*
   b *Those who provide underpaid care benefit from equity-driven improvements in work conditions, wages, benefits, and advancement opportunities.*
5 *Fundamental structural changes in institutions and policies reduce systemic inequities experienced by care workers.*
6 *Care as a social good is a collective responsibility and requires collective action by both government and care economy partners.*

Each of these components is summarized below. The strategies to reframe policies and attain each component are addressed in Chapter 7.

Core Component 1. Care work is universal and skilled labor essential to individual and societal well-being. Care is a public good with economic and social value.

Caring practices are of core value because they sustain and foster human life and society (Engster, 2007). Because care is so fundamental to our ability to function, it is possible to take it for granted and ignore it; as a result, a "cloak of invisibility" often surrounds the significance of care in everyday life (Bowden, 1997, p. 5) and makes it possible to both disregard and devalue care (Barnes, 2012). This process contributes to perceptions of care work – whether paid or unpaid – as unskilled and requiring minimal training. Yet anyone who has been a family caregiver or a home care worker – or who has closely observed their care labor – can attest to the skill involved in motivating an older person to eat or take a shower, managing medications or coordinating complex services.

Care is conceptualized by feminist scholars as a public virtue and practice central to our democratic commitments (Tronto, 1993; White, 2015). People should receive good care because they need it, not because they deserve it (Gheaus, 2010). The feminist scholar Kittay (2015) suggests that a shared conception of a social good (e.g., a common good that has public value) is that people care about each other. Care is a public good because it benefits not only the well-being of those who give and receive care but also the family, community, society, and globally for distant others (Duffy, Armenia, & Stacey, 2015; Held, 2015). Deservingness is often a criterion for social welfare programs that may further the stigma and dehumanization around receiving help. However, meeting basic needs is a fundamental right that should take priority over other societal and political concerns. With care justice, responsibility for others is a central focus of political and social life, not an add-on (Tronto, 2013).

Care work carries strong negative connotations in American society, however. These negative perceptions were identified by the Frameworks Institute, which seeks to change how the public views care work. Their research involved peer discourse sessions with approximately 80 participants in 2020 and 2022 and 160 participants in 2023 along with a culture tracking survey of a large nationally representative population. They

found that when people hear "care work," they generally think about skilled health care in hospital settings and institutions, not in the home. This reflects a persistent and pervasive perception that care work performed within the home is an unpaid labor of love while care in health care (e.g., medical) spaces is more important and skilled. The public tends tend to view home care as simply household help and companionship, akin to a babysitter, requiring "undereducated and underqualified" people (compared to medical staff) with the right personality, natural character trait, or gender to provide "help that anyone can do." Labeling care outside medical settings as "help" interferes with thinking about care in systemic terms as essential to the American economy and is a barrier to elevating care work (Frameworks Institute, 2021).

These attitudes influence how inherently difficult care work is made even more challenging by the limited allocation of public resources to support and elevate it. Although this book makes visible the indispensable nature of care labor, the structural devaluation of those who provide care is reflected in inadequate compensation, benefits, supportive services, and respect given them, especially compared to other kinds of work.

Core Component 2. The relational nature of care work, with its interdependence and reciprocity, is valued and supported.

Relationality is central to individual and societal well-being and therefore to care justice. The past gerontological focus on care as a burden or a loss-deficit model can obscure dimensions of meaning, purpose, satisfaction, and pride that often derive from relationality (Cunningham, Cunningham, & Roberston, 2019; White, 2015). Feminist theorists have long called for a revaluation and appreciation of care and mutual interdependencies across the life course, which are integral elements to the public valuing of care and thus to care justice. A care justice framework recognizes that we are never fully independent; rather, we all need care at times in our lives. From a feminist perspective, care is a human response to our mutual interdependence in networks of complex and ever-changing relationships, which require fostering to flourish (Tronto, 2013). Because of its relational qualities, care is conceptualized as a process of social cooperation and reciprocity, not a commodity or product; these social processes involve building identities and a connectedness with others (Akkan, 2020, p. 54; Kittay, 2015). Relationships are inherent to caring, but social policies markedly influence caring interconnections (Held, 2006; Tronto, 1993).

Moreover, care work requires recognition of personhood, which involves reciprocity and a sense that oneself and identity matter. The feminist scholar Harrington contends that since care is central to developing our sense of personal connection to others, "it should become a primary principle of our common life, along with assurance of liberty, equality and justice" (2000, p. 155). As noted by Coe (2019) in her ethnographic study of African immigrant care workers, care is central to the processes of belonging to humanity for both care workers and the people they support. Feminists contend that the person providing care is typically concerned with the well-being of those receiving care, who often express gratitude to care providers (England, P., 2005; Fisher & Tronto, 1990; Folbre, 2012). Recognition and gratitude are central to care justice. Since care workers need supportive connections and others' recognition to sustain their caring, sustainable just care arrangements recognize and attend to the needs of all care participants (Keating, McGregor, & Yeandle, 2021). This contrasts with individualized, competitive, and monetized frameworks underlying incremental public policies that minimize compassionate, collective responsibility toward others (Fraser, 2003; Wood & Skeggs, 2020).

Not all care relationships are positive, however. The relational nature of care work combined with power inequities, particularly for underpaid care workers, means that conflicts and mistreatment can occur. A care justice framework makes explicit the need to protect those who choose to care from exploitation, coercion, and lack of resources and opportunities (Kittay, 2015).

Core Component 3. Economic, political, and social structures empower men and women to be able to choose whether and how to care for those who need it – and to support their choice without judgment.

According to Black feminists, oppression renders a person unable to make their own choices (Biana, 2020). In a care justice framework, men and women, unpaid or underpaid, are able to choose whether and how to provide care. Moreover, economic, political, and social structures are in place to support their choice without judgment (Jecker, 2002). For families who choose to care for their older relatives, public resources must support them. Individuals, particularly those low-income and marginalized, should have opportunities to make informed decisions about home care as an occupation rather than have it be a default available position. Moreover, if they choose to pursue and remain in home care, they deserve to be adequately compensated rather than experience precarity.

Any gender- or race-based division of elder care within the family or community violates the social justice principle of fair equality of opportunity. The concept of care justice extends this principle beyond the equal participation of men and women in caring for older adults to one of equity by race, gender, class, sexual orientation, gender identity, and citizenship status. In contrast to traditional social justice goals, care justice centers structural supports for care that empower women and men to be able to choose whether to care for those who need it and thus the lives they wish to lead without profound economic, physical, or emotional costs. In his analysis of justice and family caregivers, Jecker (2002), however, acknowledges that systemic change to support the choice to care is difficult. This is because injustice is easily overlooked when it appears as an ordinary feature of everyday life, as occurs with the invisibility of care labor.

Core Component 4. Society invests in care as a public good and infrastructure where care labor is equitably organized, accessible, and sustainable.

a ***Those who provide unpaid care are valued with financial compensation to reduce care's economic costs.***
b ***Those who provide underpaid care benefit from equity-driven improvements in work conditions, wages, benefits, and advancement opportunities.***

Feminist scholars contend that the basic structure of paid care work must change to avoid inherently disadvantaging those who perform it (Reiheld, 2015). In a society characterized by care justice informed by feminism and Black feminism, the essential nature of care work is valued, accessible, and sustainable; it is equitably shared to prevent the burden of care falling disproportionately on women, communities of color and immigrants. Moreover, all care work, including family caregiving, is paid work, which elevates its importance in society.

Policymakers often oppose financial compensation to family caregivers, contending that payment makes it less loving. However, compensating families for their indispensable

work and supporting them with quality, equity-focused services acknowledges that care in the home is socially important (Poo, 2015). In a care justice framework, family caregivers have access to both material and relational supports to ensure they are able to sustain care alongside their other roles, such as employment (Keating, McGregor, & Yeandle, 2021). A care justice framework moves beyond incremental modifications and equal opportunity to equity-driven structural changes to improve working conditions and compensation and reduce systemic economic inequities for both types of care workers.

Core Component 5. Fundamental structural changes in institutions and policies reduce systemic inequities experienced by care workers.

From the perspectives of feminist, Black feminist, critical race feminist and intersectionality theories, fundamental structural change is imperative to reduce systemic inequities. Such change – within government, unions, the workplace, and the family – is the north star for care justice. It crosscuts and is the foundation for the other components. From a feminist perspective, care justice presumes the necessity of transformative structural changes to societal institutions and policies to address the distributional aspects of care responsibilities, material resources and power relations among the state, the family, and the market (Akkan, 2020; England, 2005; Folbre, 2001, 2006). As noted earlier, macro level political solutions are needed to lessen or end systemic oppression, disparities, and marginalization experienced by women, people of color, and immigrants who provide the most care (Few-Demo & Allen, 2020). The reframing of policies and programs in Chapter 7 aims to create and sustain a just caring society where care is publicly respected and elevated.

Core Component 6. Care as a social good is a collective responsibility and requires collective action by both government and care economy partners.

The imperative for fundamental changes to ensure that care is a collective, not individual, responsibility is the most transformative component and the most difficult to attain. Feminist scholars, such as Nussbaum (2003), posit that the state (e.g., government) must act to achieve equity for marginalized groups. Care justice locates the responsibility for care in the public sphere at local, state, and national levels. This location recognizes that care is the foundation or core of our social structures, not an individual moral duty. Within the public sphere, the work of care is assigned societal value because it is both a demanding, skilled activity and a public good. Care labor for those who need it does not result in second-class citizenship, but instead it is a public matter where it is normative that we are all responsible for care (White, 2015). To make care a collective and sustainable responsibility, government along with care economy partners in the service sector organize care to be accessible to all who need it and to support those who choose to receive and give care (Glenn, 2010). Policies proposed in Chapter 7 build toward care as a collective responsibility by government and by care economy partners, such as the union SEIU.

Theoretical approaches of feminism, Black feminism, critical race feminism, and intersectionality

Feminist, Black feminist, critical race, and intersectional theories are particularly salient to this analysis of how the current social organization of care creates and exacerbates the gendered and racial division of labor among those who provide care.

Feminist theory

Feminist theorists conceptualize care work as reproductive labor needed to promote well-being and sustain a productive society, whether performed by family members or hired workers. Social reproduction involves not only caring for children, but also fostering people's well-being across the life course, thus reproducing and maintaining social and economic well-being. Social reproduction is essential to the process of resource accumulation and fundamental to human survival. Analytically, this focus on collective responsibility for social reproduction challenges the prevailing assumptions of political economy in the U.S. that focus primarily on the production of individual wealth under capitalism (Duffy, Armenia, & Stacey, 2015; Luxton, 2021).

Feminist scholars emphasize the need to address the power dynamics within as well as outside of the family – the connections between public and private life (Cranford 2020; Glenn, 2010; Fraser, 2013). They contend that the gendered division of labor within the home is the cornerstone of systemic gender inequality and the devaluation of care that often carries over to the marketplace. Women's unpaid domestic labor subsidizes capital accumulation by men (Bezanson, 2006; Luxton, 2021). The unjust organization of care is rooted in the ideology of separate spheres – a capitalistic dichotomy between the public spheres of men in the marketplace and the private spheres of women within the home. The artificial distinction of public/private, money/love is grounded in assumptions concerning the "nature" of women who have been excluded from the public domain/political realm. There is little "natural" about women's challenging care labor, however. Moreover, the public and private spheres were never separate in the sense of operating independently of each other. The occupational segregation of women's work in the labor force has reinforced and reflected women's work in the household, and the reverse has also been the case.

As noted earlier, feminist gerontologists have typically addressed gender inequities within family care more than within the underpaid workforce. They have explored power inequities in the division of labor within the home and in the care of those who are "dependent." Feminists have highlighted the gender injustice of traditional ideals about the family and women's caregiving role within it. Part of the myth of women's nature and care as a private responsibility within the family is that their labor is just part of love, a choice and not "real" work while men's work in the marketplace is "productive" and profitable (Luxton, 2021). Because care labor occurs in the home, it generally remains out of sight and out of mind. The belief that care is not a public matter contributes to its invisibility and devaluation.

Increasingly, feminists give greater recognition to how unequal gender relations within the family underlie broad economic, social, and political inequalities. They contend that the contributions of women's unpaid work to the economy must be recognized as socially necessary and valued in ways that improve women's lives (Luxton, 2021). Rejecting a traditional division of labor along gender lines, feminists contend that men and women should share equally in cultivating care relations and in the paid workforce. However, the feminist goal of equality for women in the marketplace begs the question of who will do the care work at home? (Robinson, 2015). As long as care is of low status, moving care into the public sphere (e.g., home care agencies) may still perpetuate gender inequities, since assumptions that devalue care work within the family generally carry over to the paid sphere of care.

Systemic gender stratification within family caregiving translate to other inequities in the public sphere, such as when low-income home care workers, especially those who are

private pay, care for older relatives of well-paid largely professional white women (Hochschild, 2003a, 2003b). Care relationships are often both hierarchical and interdependent; one woman's low-wage work may enable another women's higher standard of living. As noted by Robinson (2015), the "empowerment" of some women in the workforce relies on the oppression of others to care for their dependents. When men or women choose not to care for older relatives and care is transferred to the marketplace, existing hierarchies in the marketplace may be further solidified, with people who are already marginalized taking on care work for low or no pay and experiencing poverty both while they are employed and into old age. Although paid care may allow higher income women to have more choice about family care, the fundamental problem of care inequities remains unaddressed. It is a manifestation of systemic sexism, racism, classism, and ageism when those who make decisions about care labor (e.g., elected officials, policymakers, and employers of home care workers) do not take account of such inequities faced by care workers (Glenn, 1992).

Hierarchical structuring of care also occurs globally, creating global care chains – a series of personal links between people across the globe based on paid or unpaid care work (Hochschild, 2012). The growing need for cheap labor to care for older adults along with the limited employment for women in many parts of the world has produced a global care economy, which is driven by care as much as by so-called productive labor (Garbes, 2022). Women with sufficient financial means often resort to hiring home care workers from a pool of undocumented immigrants. Once in the U.S., they constitute a shadow workforce paid "under the table." This results in precarious employment and unsure citizenship for women who migrate to provide care across cultures, generations, borders, and boundaries and thus deprive their families and their home countries and economies of their contributions (Ehrenreich & Hochschild, 2002; Fudge, 2012; Luxton, 2021; Poo, 2015). As noted earlier, seeking to reduce their own unpaid care in the home typically privileges white families who may make unreasonable demands on immigrant women dependent on them (Akkan, 2020). Non-Hispanic white women's reliance on the low-wage labor of women of color has deepened racial inequities in the U.S. and around the world.

Drawing a distinct line between those with power and those to be dominated, who are typically women and people of color, is central to capitalism. This gender-based division reverberates structurally, because it disempowers those who perform family care for dependents across the life course and restricts women's paid employment opportunities when they do enter the marketplace. Capitalism also segregates women, particularly women of color, in low paying, less powerful occupations than men. The predominance of women of color as underpaid home care workers means that how care work is organized and rewarded most negatively affects their economic status and health (Few-Demo & Allen, 2020).

Black feminism and critical race feminism

Central to a care justice framework, Black and critical race feminists interrogate class and race in addition to gender as central to an analysis of the social organization of care. From the mid-1970s, liberal feminism was criticized for its focus on white privileged women as a homogenous group with a clearly defined set of shared interests. Black and critical race feminists contend that feminism should be about more than ending sexism and include all who are exploited, discriminated against, and oppressed. Feminism in the

late 20th century, however, generally overlooked other forms of oppression, particularly racism, classism, and xenophobia, which furthered the oppression of non-white, non-privileged women. White heterosexual women need to need to affirm that the construction of gender goes beyond their experience and take responsibility for their roles that devalue Black and Brown women's experiences and perpetuate racism. Compared to early feminists, Black feminists give greater visibility to differences as strengths and empowerment. The uniqueness of women should be honored while not privileging one group of women over another (Biana, 2020; Crenshaw, 1989; Henry, Dicker, & Piepmeier, 2003; Hill Collins, 1990; hooks, 1984; Jaquette, 2021; Lorde, 1984).

Black feminism and critical race feminism contend that race consciousness must be considered with gender, since Black and Brown women exist within an intersectionality matrix of multiple locations and identities that women inhabit (Few, 2007). Black feminists point to how various institutions outside the family (e.g., paid work), with which Black women must daily interact, reinforce social inequities (Berridge, 2012; Few, 2007; Glenn, 1992). Black women have long been present in the public sphere, but primarily as low-wage workers who are treated as second-class citizens. This is reflected in the low pay and oppressive working conditions faced by women of color occupationally segregated in home care, other service positions and retail. For decades, Black feminists have advanced an agenda of racial, gender, economic and sexual liberation, attending to suffering and care and claiming worth for themselves and their communities. This agenda posits that care equity for Blacks includes care for one's own and demands for larger social transformation (Lake, 2023).

Black feminists highlight that those who command services from those who provide them often differ by race/ethnicity, citizenship status, social class as well as gender identity and sexual orientation. This oppressive system is referred to as racialized gender servitude, where norms of female caring are integral to efforts to control racial, ethnic, and lower class "others" (Folbre, 2012; Glenn, 2010). For example, such control undergirded the exclusion of home care workers who were largely Black domestic workers from the Fair Labor Standards Act (FLSA), and from labor reforms and federal protections for 75 years until 2015. This exclusion furthered a gendered and racialized history of care that intensified the exploitation of poorly paid care workers (Wood and Skeggs, 2020). It undergirds the lack of progress toward a living wage for care work. There are few material benefits to attract and retain people to home care, because of the historical separation of public and private spheres and the deep-seated inequities related to gender, class, race, and citizenship status.

Rooted in an understanding of Black women's lives, Black feminists seek to give to Black women an "authoritative voice" about their care experiences rather than "impose a normative gaze" (e.g., Western, white, male, middle class experience defined as normal and the standard to compare others) (Few, 2007). They challenge the exclusionary concepts of women's reproductive labor in the home as based on the dynamic between husbands and wives; this perspective excludes families such as single mother households, extended families, shared parenthood, or fictive kin that are common among communities of color. For example, African Americans tend to rely more heavily on communal forms of caring than most whites do. Shared parenthood or "other mothering" is a public practice within some Black communities, where responsibilities for care and maintaining relationships are at the center of community, not a private invisible enterprise. "Other mothering" is a strength of African American communities, not a dysfunctional family form as often defined by those with power (Collins, 2000; White, 2015).

Critical race feminists broaden the contextualization of sociohistorical experiences to include any racial or ethnic group; they focus on how laws and social policies, such as those influencing home care employment conditions, assist or oppress other racial and ethnic women and their families (Crenshaw, 1989; Few, 2007). They contend that racism, power inequities, oppression, and white privilege are built into the structure of HCBS (Morales, Miller, & Hamler, 2022). For example, the labor of home care workers of color is valued less than that of other health care providers; additionally, home care workers describe instances of racism and classism in their daily interactions with older adults, their families, and employers (Coe, 2019; Stone & Dawson, 2008). Moreover, institutional racism is found to be codified in formal and informal rules and policies for community-based care that may exacerbate inequities related to pay and career advancement for those who give (Farquharson & Thornton, 2020; Feagin & Bennefield, 2014).

Intersectional identities and systems of oppression

The identities of those involved in the process of care are relevant to care itself, pointing to the need to take account of the intersectionality of multiple identities on the experience and costs of care. Race and ethnicity intersect with class, gender, sexual orientation, citizenship status, and other bases of systemic oppression rather than separated out as abstract categories for analysis (Engster & Harrington, 2015). A care justice framework seeks to make visible the lives of people who live at intersecting junctures of oppressions with other identities across time and geography that create and further structural inequities (Collins, 2015; Hill Collins & Bilge, 2016; Few-Demo & Allen, 2020; hooks, 1981). As noted by Crenshaw (1993), intersectional theorists examine the politics of location, analyzing the complex interplay of identity, social location and systems of oppression that are embedded in institutions, policies, practices, and culture (Few, 2007). The framework of intersectionality is integral to both Black feminist and critical race feminist perspectives on care and to advancing care justice (Hankivsky, 2012; Holman & Walker, 2021) since it identifies the multiple dimensions of structural inequities faced by unpaid and underpaid care workers. Intersectionality theories compared to feminist theories give greater attention to classism, which is often not as apparent or acknowledged, in part because the poor have no public voice in society (hooks, 2000). Class is conceptualized as more than in relation to production, since it involves behaviors, basic assumptions of what a person expects from themselves and from others, their concept of a future and how they think, feel and act (hooks, 2009). The intersection of class with race, gender and citizenship status is central to a care justice framework.

By taking account of interrelated sources of oppression and privilege, intersectionality theory differs from an additive approach in which women of color who are care workers are viewed as "doubly" subordinated (Glenn, 1992; Duffy, 2005). The intersectionality framework instead provides a means to examine the multidimensionality of lived experiences of marginalized carers and the interconnections that are relevant to the exercise of power and exacerbation of inequality between those who can pay to receive care and those who give care. These multidimensional aspects of injustice are reflected in high poverty rates among female home care workers of color and among older women who were family caregivers across the life course (Liu, Chi, & Wu, 2022). By describing the intertwining of relationships among identities and categories, an intersectional approach furthers our understanding of the racial division of paid reproductive labor as productivity. Additionally, it advances analyses of how and why certain populations