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ABSTRACT

A PUBLIC ETHIC OF CARE: IMPLICATIONS FOR LONG-TERM CARE AND SOCIAL WORK PRACTICE

By

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The significant protections afforded the elderly in this country through Social Security and Medicare end when older adults become disabled and in need of long-term care services. We have no coherent system of care for frail elders; instead we have multiple and fragmented programs, each with their own attending funding streams and eligibility requirements. In spite of significant public resources allocated to long-term care, many frail elders are unable to pay for needed services, go without needed services, or receive services they neither need nor want in their attempts to patch together a plan of care. Poor quality of care pervades the delivery of long-term care services. Care-givers, both paid and unpaid, bear heavy emotional and financial burdens that threaten to unravel the fabric of responsibilities that we hold dear to loved ones and to society. These problems with long-term care are complex and deeply entrenched in cultural values and norms that define the need for care as a commodity or as a private trouble, that construct old age as a medical problem, that holds out self-determining and independent adults as the norm for human experience, and that perceives women as natural care-givers.

A public ethic of care provides a possible antidote to the problems of long-term care. Addressing several key research questions develops this argument. First, what are the constitutive elements of a public ethic of care? Second, how do current

long-term care policies stand up when analyzed through the lens of an ethic of care? Third, what contributions can an ethic of care make to thinking about the social and political issues of long-term care policy and what kinds of possibilities are opened up by reasoning with an ethic of care? Finally, what does care look like as a political idea? More specifically, what would long-term care policy look like if care were a central moral focus in our liberal, democratic, pluralistic society? The methodology used is both normative and empirical. Arguing that a public ethic of care should have a more central moral focus in our society is a normative exercise. Describing and analyzing current policies in long-term care, and the extent to which they realize an ethic of care is empirical work.

Part One reviews the philosophical and historical traditions from which a public ethic of care emerges. Part Two is a detailed problem statement of long-term care policy, evaluated through the analytic lens of a public ethic of care. Part Three works toward reconceptualizing long-term care through the lens of an ethic of care, considering how long-term care might be re-visioned if grounded in the assumptions of a public ethic of care. The conclusion brings the discussion of a public ethic of care back specifically to the profession and practice of social work, where the argument is made that a public ethic of care can inform and shape the historical commitments of the profession, and the knowledge and skills of the profession can further the implementation of a public ethic of care.

DEDICATION

To Mike,
Laura, and Ben

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Learning is seldom, if ever, an individualistic undertaking. I do not think I fully comprehended this, however, until beginning my doctoral studies. I am immensely grateful to many people, not all of whom can be named here, who have challenged and supported me through these studies.

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In spite of tremendous emotional and scholarly support throughout my doctoral studies, I am certain that the finished product is incomplete both in form and substance. For this, I take full responsibility.

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Chapter One

Setting a Context: Social Work, Long-Term Care, and an Ethic of Care

Only in regard to the elderly does the United States have social service programs resembling that of Western European welfare states (Skocpol, 1988). In contrast to means-tested programs directed to the poor, Social Security and Medicare are federally administered, universal, social insurance programs. Yet these protections end when older adults become disabled and in need of long-term care services. Medicare, based on an acute care model of health care, provides minimal assistance for care of chronic disease. For those who need long-term institutional care and are too poor to purchase it themselves, Medicaid, a means-tested program, becomes the only option.

This dissertation focuses broadly on long-term care concerns of the elderly and on the larger philosophical, political, and policy issues that shape long-term care. This is a legitimate field of inquiry for social workers, a task that accords well with Schneider and Netting's (1999) call to embrace the dilemma between addressing social issues and reform through policy influence and providing assistance to individuals as a tension that defines the profession. They write: "The uniqueness of the social work profession rests in a professional calling that disallows one-dimensional or comfortable thinking. This call to embrace ambiguity and to connect the often-invisible struggles of individuals with the more public action of decision makers in powerful positions is the essence of social work" (p. 349).

The focus of this dissertation also accords well with social worker Frederic Reamer's proposition that social workers, from time to time, make room in their professional lives to consider larger philosophical and social issues (1993). Macrosociological conditions shape the milieu in which gerontological social workers carry out their responsibilities. These conditions include such facets as the growth of an aging population, advances in medical technology that extend life but do not cure disease, increased severity of illness in nursing home patients brought about by the Prospective Payment System under Medicare in acute care hospitals, increasing unavailability of middle-aged women to serve as unpaid care-givers, a political context bent on deficit reduction and seemingly not open to increased funding of long-term care, crises in attracting professionals to geriatrics, and a market economy supportive of investor-owned nursing home corporations rather than national health insurance (Weiner and Kaysor-Jones, 1990). These are large and complex issues that cannot be adequately addressed here or by social workers in gerontological practice settings. Nevertheless, as sociologist C.W. Mills urges, social scientists have not completed their intellectual journey unless they analyze the intersection between 'personal troubles' and 'social issues' (Mills, 1959).

Although this dissertation does not by any means complete Mills' intellectual journey, it does attempt to critically evaluate and appropriate from robust and vigorous discussions in other disciplines and professions a useful conceptual perspective for social work in a particular area of practice, one that will assist the profession in carrying out its historical commitments to linking policy with individual lives. This perspective, known as an ethic of care, receives a great deal of attention from feminist thinkers in diverse disciplines including philosophy, sociology, psychology, and political science.[1] Applications of a care ethic are also considered in several professional contexts, particularly nursing and education, to such an extent that some consider replacing an ethic of justice, which is often juxtaposed to an ethic of care, with an ethic of care (Noddings, 1984; Rumsey, 1997). The work of psychologist Carol Gilligan, who explicitly raises the notion of a "different voice" in moral reasoning, the voice of care in contrast to the voice of justice, is cited over 1100 times in the *Social Science Citation Index and Science Citation Index* from 1986 through 1990 (Tronto, 1994). Tronto notes that "in every field of academic thought touched by feminist thought, from literary criticism to public policy, from business and law to nursing and veterinary medicine, Gilligan's work has been suggestive and important" (p. 77).

Gaps in the Social Work Literature

Unfortunately, little of the discussion about an ethic of care has found its way into the professional social work literature, specifically the literature that focuses on the intersections between social work, health, and aging.[2] Since Gilligan's influential *In a different voice: Psychological theory and women's development* (1982), only a handful of articles have been published in the social work literature that intentionally

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[1] Some of the more recent discussions include Benner and Wrubel, 1989; Bubeck, 1995; Fisher and Tronto, 1990; Held, 1993, 1995; Jaggar, 1995; Sevenhuijsen, 1998; Tronto, 1994.

[2] Journals searched included *Administration in Social Work, Families in Society: The Journal of Contemporary Social Work* (formerly *Social Casework*), *Health and Social Work, Journal of Gerontological Social Work, Journal of Sociology and Social Welfare, Social Service Review, Social Work*, and *Social Work in Health Care.* Search terms used included "autonomy," "care theory," "care and justice," "ethics," "ethics of care," "feminist ethics," and "self-determination."

engage the care - justice debate. In 1985, two articles appeared in the March-April volume of *Social Work*, the profession's major journal, and both were affirming of Gilligan's work in moral development (Davis, 1985; Rhodes, 1985). Davis argued that Gilligan's work could be useful to suggest gender-based remedies as new solutions to problems that appeared to be gender-neutral (such as the rift between clinical social work practitioners and academic social work researchers as reflections of different worldviews). Rhodes suggested that Gilligan's conceptualization of rights and responsibilities as contrasts corresponded to two moral traditions in social work: a needs perspective based on nineteenth century Christian virtue and a rights perspective based on liberal individualism. Recognizing the conflict between needs and rights could lead to further discussion of alternative social visions, argued Rhodes. Meyer (1985), however, in her editorial in this volume expressed skepticism about Gilligan's dichotomous thinking. "Letters to the Editor" in subsequent volumes of *Social Work* in 1985 expressed concern about the profession's possible appropriation of Gilligan's ideas in social work because of possibilities to further polarize gender differences (Levy, 1985; Proctor, 1985) while others welcomed the opportunity to re-connect justice and caring to present day practice as it had been connected at the beginning of the 20th century (Downes, 1985; Hartley, 1985). Gould (1987), critical of Gilligan and Davis' "uncritical acceptance of Gilligan's theory" (p. 411), argued that Gilligan's ideas about women's morality appealed "simultaneously to the supporters and the opponents of the status quo" and that it accomplished this by presenting a "traditional view of women that also succeeds in appealing to feminists by affirming the feminine characteristics that society devalues" (p. 412). During the

1990's, one additional article explicitly about an ethic of care appeared in *Social Work*. Freedberg (1993) examined tensions inherent in the social worker's "self-conscious commitment to care" (p. 535). She called upon women social work practitioners to couple caring with professional discipline and an empirical knowledge base.

These few articles, then, constituted the major journal of the social work profession's consideration of the care-justice debate. This debate appeared for a brief time, most intensely during the mid-to-late 1980s, and then disappeared. The numerous refinements of an ethic of care within the feminist literature informed by multiple disciplines and professions have not re-entered the social work literature in any substantive manner.

During the 1990s, a few additional articles related to an ethic of care appeared in social work-related journals. Leira (1994) discussed the concept of care as developed in Scandinavian research, and argued that the gendered division of labor produced a gendering of the social rights of citizenship. The idea of "citizen as carer" was not as valued normatively or established in terms of policy entitlements as the idea of "citizen as wage worker"(p. 197). Gummer (1996) traced the developments of ethics in administrative practice, contrasting orientations of justice and care in management. Abramson (1996) discussed the story of a young woman with AIDS, followed by an analysis of the ethical questions and issues raised in the story from the perspectives of four ethical traditions, one of which was feminist ethics. She concluded her article with a plea for expanding the "ethical repertoire of social work in appreciation of a multi-perspective approach" (p. 11).

With one exception, social work textbooks that focus on philosophical underpinnings of the profession and its values and ethical stance have not grappled seriously with the care-justice debate. Reamer's *The philosophical foundations of social work* (1993) overlooked the care - justice debate in his chapter on political philosophy even though feminists in political philosophy had begun by this time to think seriously regarding the feasibility of an ethic of care in political and social life. Likewise, social work texts on professional values and ethics overlooked this discussion. Feminist theory was allotted one paragraph in Loewenberg and Dolgoff's *Ethical decisions for social work practice* (1996). The largest part of this text was devoted to discussing ethical dilemmas that arose in professional practice. The "Ethical Rules Screen" and the "Ethical Principles Screen," grounded in Kantian and Rawlsian conceptions of justice were discussed at length; no mention was made of an ethic of care. Reamer's several texts (1990, 1999) on social work values and ethics also did not engage an ethic of care in resolving ethical dilemmas.

By contrast, Rhodes (1991) suggested that the central question in ethics should be "How ought we to act in relation to others?" (p. 43). The primacy of relationships and recognition of the centrality of social and political factors in ethical systems was her starting point. Interestingly, Rhodes did not explicitly connect these ideas to an ethic of care yet her analysis of various ethical dilemmas was often congruent with an ethic of care, and in particular, with an ethic of care as defined for this project. Rhodes' ideas, however, did not seem to have influenced the profession in a substantive way- -at least if influence is measured by ongoing engagement with her ideas in subsequent social work journals and texts.

This paucity of literature in addressing an ethic of care is disturbing given the social work profession's commitments to "individual well-being in a social context and the well-being of society" (NASW Code of Ethics, 1996, p. 1). As most seasoned practitioners experience, these dual commitments present complex and multi-faceted ethical tensions, tensions captured by an ethic of care's attention to attachment and detachment, and an ethic of justice's attention to equality and inequality. As Gilligan writes:

> All human relationships, public and private, can be characterized both in terms of equality and in terms of attachment, and . . . both inequality and detachment constitute grounds for moral concern. Since everyone is vulnerable both to oppression and to abandonment, two moral visions- -one of justice and one of care- -recur in human experience. The moral injunctions, not to act unfairly toward others, and not to turn away from someone in need, capture these different concerns (1987, p. 20).

Dissertation Focus and Research Questions

Subsequently, the broad aim of this dissertation is to assess the value of a public ethic of care as it relates to long-term care for frail elders, and indirectly, for social work policy and practice. Long-term care for frail elders, as an important sub-field of gerontology and as a viable and critical field of practice for social workers, serves as a case study through which the utility of an ethic of care can be evaluated through analyses of pertinent public and organizational policies. This dissertation is less about the specifics of social workers' roles and tasks within long-term care and more about the societal and organizational contexts in which long-term care is delivered.

More specifically, this project considers an ethic of care as it is extended to long–term care policy for the elderly in what we traditionally have considered the public sphere.[3] The argument is that an ethic of care can contribute to more effective long -term care policy at the organizational level, and that at the societal level, an ethic of care can have a transformative effect. This argument is developed by addressing several key research questions. First, what are the constitutive elements of a public ethic of care? Or, stated differently, what does care look like at the level of policies and programs within organizations? Second, how do current long-term care policies stand up when analyzed through the lens of an ethic of care? Third, what contributions can an ethic of care make to thinking about the social and political issues of long-term care policy and what kinds of possibilities are opened up by reasoning with an ethic of care? What programs and policies exist as potential

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[3] Two clarifications. First, the terms "public sphere" and "public life" are used interchangeably. Second, the intent is to consider the contributions of an ethic of care in the public sphere (in contrast to the private sphere, usually considered to be the family). In very general terms, the public sphere is understood to consist of the activities and coordinative efforts of the state, the economy, and voluntary associational life. The analysis here is not comprehensive of these three arenas. Instead, examples of specific activities of the state, especially its role in setting public policy for long-term care of the elderly, are investigated; lesser attention is given to the economy. Following Young (2000), the public sphere can also be considered more narrowly as the activities of particular types of voluntary associations, particularly political associations (and in some instances, civic associations). Here the public sphere is constituted as a site for communicative action and contest among a plurality of citizens with diverse interests, experiences, and values who yet work toward presenting their case in a manner that is accountable and accessible to anyone. The aim of action in the public sphere, according to Young, is to "influence or reform state or corporate policies and practices" (p. 163). This more narrow understanding of the public sphere is developed more fully in Chapter Six.

models- -programs and policies that affirm an ethic of care when care is used as an analytic tool? Finally, what does care look like as a political idea? More specifically, what would long-term care policy look like if care were a central moral focus in our liberal, democratic, pluralistic society?

The remaining pages of this chapter set the stage for the work ahead. The key ideas of subsequent chapters and methodology are identified next, followed by a discussion of the contributions this dissertation hopes to make to social work and the larger disciplinary and professional conversation about an ethic of care. Finally, a broad overview of long-term care is presented. This serves as a starting point in subsequent chapters for analyzing long-term care policy though the lens of an ethic of care.

Subsequent Chapters

Part One of this dissertation reviews the historical and philosophical literature regarding an ethic of care. In addition to serving the purpose of reviewing the literature, this section aims at two further tasks. A conceptualization of a public ethic of care is developed from the review; this conceptualization of a public ethic of care is used as a framework for evaluating and revisioning long-term care in subsequent chapters. Part One also articulates and develops three normative assumptions about an ethic of care that inform this dissertation. First, briefly stated, it is theoretically possible and morally important to extend an ethic of care to the public arena; arguments that an ethic of care is appropriate only for use within the private sphere are rejected. Second, an ethic of care cannot replace, nor is it superior to, an ethic of justice. Forming ethical judgments and developing institutional and public policies that are both caring and just is a complex task, and both ethics must inform such deliberations. Finally, a public ethic of care that is integrated into our conceptions of democratic citizenship, and that takes its place alongside concepts of equality and liberty as central norms in our lives, is free from objectionable "feminine" associations (i.e., that caring is an *essential* attribute of women) that historically has assigned the tasks of caring to women.[4] These normative assumptions, however, require discussion as they have not been central themes in the social work literature.

Chapter Two of Part One identifies and summarizes the primary themes from the well-rehearsed Kohlberg-Gilligan debate, and points to the philosophical traditions from which these differences emerge. The tension evident in Gilligan's work between those who espouse an ethic of care and those who reject it because of its seeming confinement of care to women, and confinement of both care and women to the private sphere, is also examined. Developments in the profession of social work are used as a lens through which to consider these tensions as well as to highlight that the issues Gilligan's ethic of care raises are not new issues. Chapter

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[4] The intentional use of the 'feminine' and 'feminist' approaches to ethics draws upon a common distinction between the two in feminist thought. This difference is succinctly captured by philosopher Betty A. Sichel who writes:

> 'Feminine' at present refers to the search for women's unique voice and most often, the advocacy of an ethic of care that includes nurturance, care compassion, and networks of communications. 'Feminist' refers to those theorists, whether liberal or radical or other orientation, who argue against patriarchal domination, for equal rights, a just and fair distribution of scarce resources, etc. (1991, p. 90).

Similarly, Susan Sherwin observes that feminine approaches to ethics "consists of observations of how the traditional approaches to ethics fail to fit the moral experiences and intuitions of women" while feminist approaches apply "a specifically political perspective and offers suggestions for how ethics must be revised if it is to get at the patterns of dominance and oppression as they affect women" (1992, p. 42).

Three considers the traditional ontological, epistemological, and methodological differences between an ethic of care and an ethic of justice as well as the relationship between the two ethics. From this, a working definition of a public ethic of care is developed. This conceptual definition becomes the framework for analyzing an ethic of care as it is extended to the public sector.

Part Two is a detailed problem statement of long-term care policy, evaluated through the analytic lens of an ethic of care using the framework for a public ethic of care set forth at the end of chapter three. Chapter Four evaluates current long-term care policies and practices in terms of Tronto's (1994) stages of "caring about" and "caring for."[5] These stages, as discussed later, correspond to larger macro issues in policy analysis. Chapter Five continues this evaluative analysis, using Tronto's stages of "care-giving" and "care-receiving." These stages focus on organizational policies that shape concrete practices of care work.

While Part Two seeks to analyze and evaluate the problems of long-term care, Part Three works toward reconceptualizing long-term care through the lens of an ethic of care, considering how long-term care might be revisioned if grounded in the assumptions of a public ethic of care. To frame this in the language of social work, the question is one of how long-term care might be different if intervention consisted of operationalizing a public ethic of care for long-term care. Chapter Six revisions long-term care in terms of Tronto's phases of "caring about" and "caring for," again,

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[5] Tronto's (1994) understanding of an ethic of care is addressed more fully in Chapter Three. In summary, she conceptualizes an ethic of care in terms of four phases: caring about, caring for, care-giving, and care-receiving. This framework is first set forth by Fisher and Tronto (1990) but is developed more fully in *Moral boundaries* (1994).

a more macro analysis, while Chapter Seven revisits the phases of "care-giving" and "care-receiving."

The conclusion of this dissertation, Chapter Eight, brings the discussion of an ethic of care back specifically to the profession and practice of social work. Several foundation areas that ground the profession- -policy, research, and practice- -are explored in terms of how a public ethic of care might inform and shape these areas. The contributions the profession might offer to a public ethic of care are also explored.

Methodology

The way in which this work proceeds is both normative and empirical. Arguing that a public ethic of care should have a more central moral focus in our society is a normative exercise. As a normative project, Young's (1990) conceptualization of a critical methodology "which projects normative possibilities unrealized but felt in a in particular given social reality" is utilized (p. 6). To identify ideal practices and relations of a public ethic of care, existing care practices and care relations historically, politically, and socially contextualized in long-term care are identified to discover what is useful in them, even if present only partially or potentially. This analysis reveals deficiencies in current arrangements and at the same time, opens the door for envisioning new possibilities commensurate with an ethic of care. This analysis also underscores that facts which seem immutable and solid, such as women as "natural" care-givers or carework as belonging to the family, "may actually be largely shaped by the changeable conceptual categories we use to make sense of the world, the questions we ask to elicit the facts, or the importance we assign to the answers" (Teno, Nelson, and Lynn, 1994, p. S32). Part Two focuses on deficiencies in current long-term care arrangements when an ideal of a public ethic of care is utilized; Part Three begins to envision new possibilities that accord with the ideal of a public ethic of care.

Describing and analyzing our current long-term care system, and the extent to which it realizes or falls short of an ethic of care is empirical work. Following current strategies employed in social work policy analysis,[6] policies and the effects of these policies in long-term care are examined using the framework for a public ethic of care articulated in the conclusion of Chapter Three as an explicit analytic frame. Empirical data that documents the effects of various policies related to long-term care can uncover to what extent policies are effective or iatrogenic, can lead to policy changes that will more effectively integrate a public ethic of care into public deliberations or, conversely, lead to rethinking normative assumptions about the utility of an ethic of care as a basis for public policy.

Contributions to the Literature and Profession

This dissertation contributes to three interrelated subjects: the larger disciplinary and professional conversation regarding an ethic of care, long-term care, and the social work profession. This critique furthers the larger disciplinary and professional conversation about an ethic of care in at least three ways. First, this dissertation aims to respond to the challenge of several scholars who espouse an ethic

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[6] Chambers (2000) method of policy analysis is the primary method of analysis used here. Chambers' method, in particular, is used because he is one of few policy analysts who is intentional and explicit about the inclusion of normative ideals- -what he calls "value critical" ideals- -in and upon policy analysis work.

of care and who suggest that further thinking about care "must take place in concrete situations or with regard to specific moral voices and vocabularies" (Tronto, 1999, p. 116).[7] This kind of work is only beginning;[8] specific attention here to long-term care furthers this discussion.

Second, this dissertation addresses and attempts to resolve a particular thorny problem inherent in an ethic of care, the problem of needs. As discussed later, an ethic of care is grounded in attentive, responsive, and competent practices of meeting individual needs. On its own, however, an ethic of care has no way of defining needs, sorting out needs from desires, or prioritizing needs in cases where not all legitimate needs can be met. The solution proposed here is that an ethic of care must turn to the resources of deliberative democracy. This is a strategy seldom, if ever, made by those who espouse an ethic of care, and an argument is made for the congruence between the two.

Third, while the language of a public ethic of care is used to contrast it from earlier feminine notions of an ethic of care which confined care practices largely to women in the private sphere, the constitutive elements of a public ethic of care are not clearly articulated in the literature. Here, the constitutive elements of a public ethic of care - - care that begins with a public discussion of needs, that is contextually grounded in the experiences and perceptions of those giving and receiving care, that

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[7] Similar challenges have been levied by Bowden (1997), Bubeck (1995), and Hekman (1995).

[8] Sevenhuijsen (1998) considers a public ethic of care in regards to two issues: the Dutch public debate on child custody, and a case study of the Dutch *Choices in health care* policy document of 1991. Clement (1996) points to, but does not develop, two possible public applications of care, maternal pacifism and public provision of elder care.

affirms a social conception of the self, that prioritizes relationships, and that firmly connects to a theory of justice and is democratic in nature - - are identified and serve as a framework through which to evaluate current public and organizational policies that shape and direct long-term care.

This dissertation also contributes to re-visioning long-term care. Critiques of long-term care's economic and medicalized discourse are not new. What is new here, however, is the use of a public ethic of care to open up new ways of conceptualizing, justifying, and implementing richer and more satisfying policies for those who need care and those who wish to provide care. A public ethic of care becomes an organizing concept for implementing and evaluating concrete care practices between frail elders and their care-givers. Likewise, it assists in analyzing the extent to which institutional and public policies promote good care, and the extent to which organizations and larger social structures impede good care. Although public and institutional policies in and of themselves cannot care for frail elders, organizations can consciously arrange their policies, practices, and programs to reflect- -or not reflect- -a public ethic of care. Similarly, the larger societal ethos out of which public policy for long-term care emerges can reflect a public ethic of care by its recognition of human interdependence and the need for care throughout one's life as a legitimate basic human right. This contrasts greatly to current constructions of care that view care as an economic commodity that those with resources can purchase, or as something that only needy and dependent others require throughout their lives or enroute to becoming an independent and autonomous person.

When it is recognized that care is central to human flourishing and well-being throughout the life cycle, we must think carefully about how current institutional and public long-term care policies and policy proposals support care. Does a commitment to a public ethic of care, for instance, have an argument to make regarding how long-term care should be financed? Does a public ethic of care have anything to say about who should assume responsibility for providing such care, and what social and economic supports need to be in place to support those who do the work of care? Does a public ethic of care provide direction about how good care should be defined and evaluated? Answers to these questions, emerging from critical engagement with the ideas of a public ethic of care, will challenge current practices and policies that shape long-term care and offer an alternative framework within which to deliberate.

Finally, this dissertation contributes to several issues within the social work profession. An important and significant outcome of this work is to appropriate a public ethic of care that is congruent with social work commitments and useful to furthering social work's mission. Social workers already have demonstrated commitments to justice frameworks but as noted earlier, seem unaware of the larger lively social and political conversation regarding an ethic of care. This is unfortunate, given the potential resources of an ethic of care to further what social work affirms. Subsequently, using long-term care as a focus of analysis, this dissertation stands at the interstices between larger and often abstract and theoretical treatises on an ethic of care, and "the trenches" where social workers, other care workers, and care-givers carry out their daily work, and makes a case for care's utility in the profession.

Why is a public ethic of care useful and important to appropriate for the social work profession? Tronto (1994) argues that competent care practices hold promise for undoing current moral dichotomies[9] and "allow us to move towards a more just and caring society" (Tronto, 1994, p. 21). Just as changes in the social, economic and political order of the eighteenth century raised different kinds of moral questions, subsequently ushering in universalistic moral theory to address these questions, Tronto argues that the twentieth century raised new questions, and thus required expanding our moral terrain. It was a century in which "caring patterns have been disrupted everywhere" (p. 151). Caring functions, such as caring for small children or frail elderly, were absorbed into market spheres where often only those with privilege defined what constituted care needs and had the resources to meet such needs. The twentieth century was a century of "almost unprecedented global brutality, including two world wars, the invention of weapons of mass destruction..., numerous examples of genocide, unprecedented global migrations of peoples" (p. 151), and such disruptions have affected the abilities of millions to secure basic needs such as food and shelter.

These changes in our social and economic order do not require that social workers abandon their commitments to an ethic of justice. What is required, however, is an awareness that in spite of rich traditions of justice, insufferable social, economic, and personal injustice persists. The plight of ten million African children orphaned by the AIDS epidemic, or forty-four million Americans without health

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[9] One of the artificial moral dichotomies Tronto delineates is delegating an ethic of justice to the public sphere and an ethic of care to the private sphere.

insurance, requires not only an ethic of justice but also an ethic of care. The ethical components of an ethic of care- -attentiveness, responsibility, competence, and responsiveness- -require that commitments be carried out as practice.[10] Enlarged understandings of ourselves as socially constituted, expanding our ways of knowing to include the concrete and particular, and acknowledging the significance of relationships to human well-being serves to highlight the interdependence of each ethic upon the other, and as Narayan (1995) argues, provides the "enabling conditions" for the moral adequacy of the other ethic. For an ethic of care to be realized as a legitimate and equal partner with an ethic of justice, and for carework and care-givers to be valued in society, it must, as Tronto (1994) argues, find its way into public life such that political and social institutions reflect care's centrality.

The profession of social work historically has been committed to serving disenfranchised persons. This includes those who by their neediness and dependency are seen as the "other," and those who do the work of care, disproportionately people of color and women. Given social work's commitment to those on the periphery - - those who become the "other" by virtue of their neediness, and those marginalized because of their care-giver status- -- a public ethic of care can inform social work's commitments.

Appropriating an ethic of care for social work requires more than just making connections between the two. Rather, several complex tensions must be negotiated to appropriate a public ethic of care for social work. Successful negotiation of these

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[10] These ethical components of an ethic of care are discussed in Chapter Three in the context of articulating an ethic of care.

tensions contributes to the larger discourse regarding an ethic of care, and strengthens the argument that a public ethic of care can further social work commitments. Several of these tensions- -the problem of needs and articulating the constitutive elements of a public ethic of care- -have already been noted.

One further tension, already addressed in the philosophical literature but necessary to import to social work, is that for an ethic of care to be useful for social work, the argument must be embraced that extending an ethic of care beyond its traditional private boundaries is indeed a good and possible endeavor. Not all agree. Some (i.e., Ferguson, 1984; Noddings, 1984) argue that an ethic of care's emphasis upon contextuality, a social conception of the self, and maintaining relationships render it ill-equipped to deal with perplexing public and organizational policies and politically complex allocation decisions. Contextuality would seem to limit caring efforts to those whom we know and to those with whom we can interact. Nel Noddings (1984) suggests that caring, by definition, implies not just caring about but caring for, and caring for requires actual encounters. Similarly, seeing ourselves as socially constituted would seem to encourage us to care about those to whom we are connected, but given that it is impossible to comprehend ourselves as connected to all human beings, the scope of an ethic of care is seemingly limited. Furthermore, caring only about those to whom one is connected can quickly become unjust in its preference for partiality. While partiality is legitimate, even required, in the private sphere, it is inappropriate in public life. In terms of its prioritizing of relationships over equality, in the public square we are faced with the reality that we cannot in fact meet everyone's needs. Here an ethic of care, with its "warm, mushy and wholly impossible politics of universal love" is useless in making difficult allocation issues (Ferguson, 1984, p. 172). Clement (1996) summarizes these perceived limitations of an ethic of care in this way: "In some way, it would be *impossible* to expand the ethic's application beyond personal relations; in other ways it would be *morally wrong* to do so; and in still others ways, it would be *morally unhelpful* to do so (p. 19). In short, these limitations seem to confine care to the private sphere; given that we cannot care for everyone, we must rely on some conception of justice to meet moral obligations.

In subsequent chapters, a response to these criticisms is developed more fully; in doing so, it becomes apparent that extending an ethic of care into the public sphere is both possible and morally desirable.[11] Movement in this direction is important to correct for justice-based distortions of the self as an individualistic construct and the privileging of abstract principles over concrete rules in ethical decision-making. A public ethic of care can challenge such distortions, offering moral guidance in the public sector that will result in more perfectly targeted elder care policy. A successful rebuttal to those skeptical of extending an ethic of care beyond the private sector is an important tension to resolve if social work is to make use of a public ethic of care.

This dissertation also contributes to the development of social work

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[11] For now, in response to these criticisms, it is important to note that these traditional dichotomies are presented as ideal types and thus some of the conflict between the two ethics arises from rigid thinking that insists on either an ethic of care or an ethic of justice. It is also important to note that these distinctions are socially constructed, and that by revisiting these constructions, we can begin to construct alternative ways of understanding the discussions about care and justice.

knowledge in philosophy and ethics. The paucity of social work literature about the ethics of care is striking in a profession committed to furthering both justice and care. If the profession is truly committed to individual well-being and social and economic justice, it must find a way to acknowledge and affirm both an ethic of care and an ethic of justice, and understand at a philosophical and practice level how both are necessary in the development and implementation of social welfare policy. Reamer (1993) reminds us that:

> . . . at some points in our professional lives we must be willing to make room to reflect on the larger issues. These are the ideas that helped to inaugurate social work and give it shape and meaning. While the profession's principal impetus must always be focused on the delivery of services to individuals, families, groups, communities, and so on . . . we cannot afford to neglect the enduring philosophical concerns that launched the profession in the first place and that have served as its compass . . . . Moreover, we must recognize that both the questions we address and the answers we produce may change over time, as a function of shifting political contexts and contemporary events (p. 196 - 197).

In terms of social work knowledge and ethics this project is also significant because it extends our discussion of ethics beyond what is often a narrow focus of ethical dilemmas in direct practice where such discussions tend to be descriptive rather than analytic. Various dilemmas encountered by professionals are described; if and when ethical decision-making frameworks are applied to these frameworks, they are grounded in deontological frameworks. The principle of autonomy, for instance, while highly valued by the profession, is not without criticism in the field of social work. Tensions between autonomy, often expressed in the language of self-determination, beneficence, or enhancing the well-being and best-interests of others, and paternalism are frequently considered in the social work literature in the context of specific practice dilemmas.[12] Less frequently addressed are tensions that arise between self-determination and the ethical responsibilities social workers have to the broader society as articulated in the NASW Code of Ethics. Here we find an emphasis upon promoting "the general welfare of society," advocating "for living conditions conducive to the fulfillment of basic human needs," promoting "values and institutions that are compatible with the realization of social justice," and being aware "of the impact of the political arena on practice" (NASW Code of Ethics, 1996, p. 26 - 27). Similarly, social workers often do not consider carefully the ethical import of social welfare policy, or if they do, such considerations do not make their way into the professional literature. This dissertation broadens such a discussion, urging that the profession extend its philosophical and ethical repertoire, and turning to a public ethic of care to inform such attempts.

Long-Term Care in the United States: An overview

The goal of long-term care is generally recognized as one of helping persons live as independently as possible for as long as possible. An ideal long-term care system should include a full "range of services that addresses the health, personal care, and social needs of individuals who lack some capacity for self care" (Kane,

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[12] See, for instance, Abramson, 1985,1989; Bernstein, 1960; Imre, 1982; Murdach, 1996; Reamer, 1983; Rothman, Smith, Nakashima, Paterson, and Mustin, 1996.

1982, p. 4). The need for long-term care is often assessed in terms of the extent to which one requires assistance with or supervision in activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs are routine and basic tasks of life, such as walking, eating, bathing, dressing, toileting, and getting in and out of bed while IADLs are additional activities necessary for independence. These activities include such tasks as preparing meals, using the telephone, managing medications and money, and shopping for groceries, and getting to places within walking distance. Long-term care also includes skilled and therapeutic care to treat and manage chronic conditions (Feder, Komisar, and Niefeld, 2000).

Both formal and informal providers deliver long-term care services. Formal providers include nursing home care, home care,[13] senior centers, and adult day-care providers. Services provided in these formal settings are delivered by health care workers, social workers, home health aides, and occupational and physical therapists. Informal providers of care are families and friends who provide care in the community.

More than 12 million people in the United States need long-term care. A little over one half of these persons (6.6 million) are over the age of 65.[14] Among the elderly in need of long-term care, 2 million reside in over 19,000 nursing home

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[13] The term "home care" is used for ease of communication but not without reservation. An increasing number of long-term care consumers prefer terminology such as personal assistant services (PAS) or personal attendants, terminology that suggests care beyond the confines of the home intended to help one live as "normally" as possible in a variety of contexts and suggests care that is broader in its goals than medical or rehabilitative services (Kane, Kane, and Ladd, 1998).

[14] This elderly group of persons in need of long-term care are the focus of this project. Any comprehensive solution to the problems of providing long-term care must address the needs of the younger disabled population as well.

facilities while the remainder live in the community (Gillick, Berkman, and Cullen, 1999).[15] In contrast to other adults, persons who need long-term are disproportionately low-income, over the age of seventy-five, and living alone or with someone other than a spouse (Komisar and Niefeld, 2000).

Nursing home facilities serve a diverse population. Residents differ from each other in terms of life expectancy, prognosis, length of stay, and health status, and goals for care. Comatose patients, terminally ill persons, patients recuperating from a bout of illness and acute care, patients in need of rehabilitation, residents with persistent long-term care needs who are cognitively intact, and those with long-term care needs who are cognitively impaired constitute, in broad strokes, those persons using nursing care facilities (Kane, Kane, and Ladd, 1998). Each of these groups has their own specific care needs, capacities for autonomy, and environmental requirements.

Likewise, home care serves a diverse population and various models of home care exist (Cox and Ory, 2000). High-tech home care provides complex medical care to persons in the home. Hospice models focus on the needs of terminally ill persons and their families. Skilled nursing care in the home focuses on rehabilitation for homebound persons who are in need of intermittent care as ordered by a physician.

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[15] Individuals are described as living in the community regardless of whether they live in their own home, in relatives' homes, or in non-institutional settings such as continuing care facilities, adult foster care homes, or assisted living facilities.

Finally, low-tech home care models are designed for chronically ill or disabled persons who need custodial care to maintain functional status.[16] The services of various home care models can be considered according to five broad categories or activities, including convalescent, rehabilitation, and hospice services, activities to support ongoing and routine needs, and respite care for family members (Kane, Kane, and Ladd, 1998).

Public funding streams for long-term care consist primarily of benefits emanating from Medicare, Medicaid, and the Older Americans Act.[17] Medicare, a social insurance program for all people aged 65 or older who are eligible for Social Security, focuses primarily on coverage for acute care. Medicare becomes part of the continuum of long-term care indirectly through its provisions for limited skilled nursing facility care and directly through its small but rapidly growing home health care provisions. In terms of home health care, Medicare pays for a limited amount of home health care, subject to strict eligibility rules. Such care must be prescribed by a physician only for persons who can be rehabilitated. Medicare does not cover general household maintenance services that help people manage their daily lives; instead it covers nursing, physical therapy, occupational therapy, speech therapy, medical social work, and home health aides when skilled services are considered necessary. The high-tech, skilled nursing home care, and hospice care models (noted above) have emerged from current structuring of Medicare benefits. Medicare also covers

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[16] Even though the low-technology kind of home care is what the elderly have the greatest need for, Medicare does not pay for this kind of care and Medicaid payment is limited. These ironies are returned to later.

home hospice under a different set of requirements for terminally ill persons who have decided to forgo life-prolonging therapies. In 1999, Medicare benefits were extended to nearly 39 million Americans (nearly 34 million age 65 or older) at a projected cost of $231 billion (Smith, Heffler, Freeland, et. al., 1999).

Medicaid, by contrast, is a grant-in-aid program that helps states pay for medical assistance for certain individuals or families with low income and few resources. In 1999, Medicaid benefits were extended to over 36 million Americans (4.7 percent over the age of 65) at a projected total cost of $182 billion ($108 billion from the federal budget and $74 billion from state budgets) (Smith, Heffler, Freeland, et. al., 1999). Medicaid must be extended to elderly persons eligible for Supplemental Security Income; states may opt to extend Medicaid to older people who have incomes above SSI eligibility but below the federal poverty guidelines, and to institutionalized elders with incomes and resources below specified limits. Medicaid enters the long-term care arena in two ways. First, it covers long-term nursing home care for frail elders (those in the optional categorical need category) and, in some states, to the medically needy who have been allowed to "spend down" to Medicaid eligibility. The main source of public funding for nursing home care is, in fact, through Medicaid. Second, Medicaid also provides more limited home care through its Home and Community-Based Services program (HCBS).

Additional public payers for long-term care include the Social Services Block Grant (authorized by Title 20 of the Social Security Act), the Older Americans Act

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[17] Other sources of funding, not directly related to long-term care but certainly important social policies for the elderly include Social Security, Social Security Disability Insurance, and Supplemental Security Income.

(OAA), and the Veterans Administration. Although Title 20 funds are more flexible than Medicaid, these block grants have not kept pace with inflation; consequently it is often to a state's advantage to use Medicaid's waiver program. The provisions of the Older Americans Act include social services designed to enhance independent living and includes such things as congregate meals, personal care and nursing services, day care, chore services, and meals-on-wheels. It also provides funding for senior centers. Although these services were intended to be available to all older adults, insufficient funding - - about $1.2 billion in 1998 - - has prevented the OAA from being fully implemented.[18] Instead, OAA services are "gap filling" and targeted to people with the greatest social and economic need (Takamura, 1999). Much of the funding for low-tech home care is funded by provisions of the OAA. Services provided by the Veteran's Administration tend to be medically oriented, and are restricted to veterans.

The financing of long-term care is complex. In 1998, total nursing home and home care expenditures amounted to approximately $150 billion dollars in the United States. Forty percent of this was financed by Medicaid, twenty-six percent by out-of-pocket contributions, twenty percent by Medicare, eight percent by private insurance, and the remaining seven percent by a combination of miscellaneous sources (Burwell, 1999; Feder, Komisar, and Niefeld, 2000).[19] Total public long-term care

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[18] Medicare and Medicaid regulations can be located online at www.hcfa.gov. Further detail re the Older Americans Act, including updates on reauthorization of the OAA, can be located online at www.aoa.dhhs.gov.

[19] The public miscellaneous funds include such sources as the Older Americans Act, Title XX Social Services Block Grants, the Veterans' Administration and Civilian Health, and the Medical Program of the Uniformed Services (CHAMPUS) (Binstock and Cluff, 2000).

expenditures account for 0.7 percent of the gross domestic product (GDP); total long-term care expenditures account for 1.3 percent of the GDP (Anderson and Hussey, 2000).

Two-thirds of long-term care spending ($100 billion) is spent on nursing home care. Medicaid finances approximately forty-four percent of nursing home care while thirty-one percent is financed by out-of-pocket contributions.[20] Fourteen percent of nursing home care is financed by Medicare, seven percent by private insurance, and the remaining five percent by a combination of miscellaneous sources (Burwell, 1999; Feder, Komisar, and Niefeld, 2000).

Even though two-thirds of long-term care spending is allocated to nursing home care, eighty-eight percent of those in need of long-term care reside in the community. In contrast to Medicaid as a major funder of nursing home care, the majority of home care is funded by Medicare. In 1998, forty-two percent of home care was financed by Medicare, twenty-one percent by out-of-pocket contributions, fifteen percent by Medicaid, eleven percent by private insurance, and the remaining eleven percent by a combination of miscellaneous funds.[21]

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[20] For the elderly to qualify for Medicaid, they must meet stringent limits on income and assets. These limits are generally those applicable under the Supplemental Security Income cash assistance program, an amount of $494 per month in 1998. They must also have limited assets, usually $2,000 or less, as set by states.

[21] These percentages are based on actuarial tables from the Health Care Financing Administration (Feder, Komisar, and Niefeld, 2000). It is important to note that total home care spending is difficult to estimate due to limitations of data sources as well as profound changes in Medicare imposed by the Balanced Budget Act (BBA) of 1997. For instance, the National Association for Home Care estimates total spending for home care was $41 billion in 1997 and declined to $36 billion in 1999. Medicare spending for home care fell from $14 billion in 1998 to $9.5 billion in 1999, a thirty-two percent decrease. These declines are due largely to the result of dramatic decreases in Medicare home health benefit brought about by the 1997 Balanced

Future needs for providing and financing long-term care are unpredictable. Functional difficulties that require long-term care assistance could be reduced or delayed given new medical treatments, technological developments, and healthier lifestyles; conversely, such developments might mean that people will live longer with disabling conditions and cognitive impairments. Cohorts that reach old age in the coming decades will be better educated and higher levels of education are correlated with lower levels of disability and need for care (Waidmann and Liu, 2000). On the other hand, from 1990 to 2050, the nonwhite elderly population will more than double (from 9.8 percent to 21.3 percent). If current patterns of economic resource distribution continues, this group is more likely to be dependent on public subsidies for long-term care.[22] Prediction is also difficult because reliable data bases for making projections about disability are limited and vary tremendously from state to state regarding various types of disability.

Even though it is difficult to project future needs for long-term care, the large increase in absolute numbers of the elderly suggest that more long-term care will be needed because in general, as people age, the prevalence of impairment increases.[23] As evidence of this, Kane, Kane, and Ladd (1998) report that while only 2.4 percent of those under the age of 65 met the criteria for functional impairment, 9.2 percent of

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Budget Act (National Association for Health Care [NAHC], 2000). This is discussed in more detail later.

[22] Among persons aged 65 or older who have the lowest household incomes, nearly 40 percent are members of racial minorities; their net aggregate worth is less than one-third that of older white persons (Crystal, 1996).

[23] From 1990 to 2030, the number of persons aged 65 and older will increase from 31 million to 65 million. The number of persons in advanced old will increase as well. Between 1990 and 2030, the number of persons aged 75 and older will increase from

those between age 65 and 69 met such criteria and 49.5 percent of those age 85 or older. Furthermore, present rates of nursing home use indicate that impairment increases as people age. Currently, about one percent of Americans aged 65 to 74 are in nursing homes compared to 6.1 percent of persons aged 75 to 84, and 24 percent of people aged 85 or older (Binstock, Cluff, and von Meyering, 1996). Among home health care users, 1.1 percent of those under age 65 received at least one formal home health visit in 1996 in contrast to 13.8 of those age 65 or older (NAHC, 2000).

Overarching Concerns in Long-Term Care

Several concerns span both home care and nursing home care.[24] These include payment for services, fragmentation of services, lack of services for some, a lack of fit between available services and the needs of older adults, care-giver concerns, and quality of care issues.

Frail elders in need of long-term care are confronted with dozens of federal programs, and hundreds of state and local programs that provide funding for long-term care services. In spite of what might appear initially to be an adequate source of financial assistance, many patients and care-givers find themselves ineligible for services and unable to pay out-of-pocket for such services. As noted earlier, twenty-six percent of all long-term care (1998 dollars) is financed by out-of-pocket contributions (Burwell, 1999; Feder, Komisar, and Niefeld, 2000). The costs of nursing home care, an average of $46,000 per year in 1995, are prohibitive for many

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13 million to 30 million; those aged 85 will increase from 3 million to 8 million (Binstock and Cluff, 2000).

[24] These concerns are discussed in greater detail in Part Two and Part Three in the context of evaluating and re-visioning long term care through the lens of an ethic of care.

(Weiner and Stevenson, 1998). More than one-third of all nursing home residents "spend down" to Medicaid to cover these costs, a process demeaning for many. Some home care services, in spite of Medicare subsidization, are too expensive for most to purchase. For example, a convenience sample of 917 homebound elders in Florida were asked about their ability to meet various home care and health needs. Forty-nine percent of the population was not always able to pay for needed medications, 42 percent were unable to always pay for physicians' services, and 41 percent were not able to secure transportation to physician's office. Income security and requests for more affordable in-home services were cited most frequently by these elders as critical needs (Vinton, Altholz, and Marcus, 1997). The results of a 1995 national survey found that one in five adults with long-term care needs who live in the community report an inability to get the care they need, often with serious consequence. One of the primary reasons noted for not being able to get the care needed was services that are too expensive (Feder, Komisar, and Niefeld, 2000). Private long-term care insurance policies are unaffordable for many and often inadequate in their coverage.

A second problem, well-documented in the literature, is that services are fragmented and disjointed, and rarely coordinated with various funding streams. In spite of the fact that there is no bright line between acute and long-term care, Medicare finances acute care while Medicaid finances long-term care (Kane, Kane, and Ladd, 1998). Medicare is the primary funder of home care services while Medicaid is the primary funder of nursing home care. Furthermore, within these broad divisions of home and nursing care, specific provisions of service are divided between various public payers and private pay. Home care agency services (such as rehabilitation, convalescence, hospice, ongoing, and respite services), for instance, are separated out by different payment programs and require those in need to patch together a care plan. Within nursing homes, a fragmented system of care for frail elderly is supported by a reimbursement system that rewards physicians and hospitals for transferring patients to acute care hospitals (Ouslander, Weinberg, and Phillips, 2000). Better integration across services and programs is needed but thus far, integration occurs primarily through capitation (in contrast to fee-for-service) in managed care; this reflects "a continued quest for cost containment, at least as much as it does a pursuit of high-quality care" (Feder, Komisar, and Niefeld, 2000, p. 51).[25]

Furthermore, fragmentation is exacerbated by the fiscal tug of war between Medicare and Medicaid, a war whose casualties are frail elders. When Medicare expanded home health care benefits, this allowed states to shift some costs of care to Medicare. Some states have adopted policies to maximize Medicare revenues as fully as possible (because Medicare is fully federally funded) before seeking Medicaid reimbursable services. One recent study of home health expenditures suggests an inverse relationship between Medicare and Medicaid home health spending. As Medicare shrinks under the Balanced Budget Act (BBA), evidence suggests that coverage for the near poor is not being picked up by Medicaid (Wiener and

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[25] About 17 percent of beneficiaries are currently enrolled in Medicare managed care plans, and although performance outcomes are limited, emerging evidence suggests that for chronically ill persons, reduced service use and worse outcomes in terms of home care and rehabilitation have been found. (Feder, Komisar, and Niefeld, 2000; Shaughnessy, 2000).

Stevenson, 1998).[26] Some of the service and funding fragmentation could be reduced by having funding "follow" persons, rather than having services flow from funding. In 1993 the Health Care Financing Administration (HCFA) sponsored a conference on "beneficiary-directed" services where then-administrator Bruce Vladeck argued: "The first and most difficult issue is that to build a client-centered, beneficiary-oriented long-term care system, the dollars should follow the clients. Funding should probably not be limited to a particular kind of provider or service, or to a particular bureaucratic category, such as 'skilled' level of care" (Kane, Kane, and Ladd, 1998, p. 134). Such a change is easier said than done, however, because "funds have already been invested in existing services, and vested interests surround them. Also it is difficult to begin a new model of benefits that follows the consumer while still paying for the old categorical model that funds specific service streams" (p. 134).

A third overarching concern about the state of long-term care today is that some frail elders fall through the cracks, entering a "no care zone" (Estes, Swan, and Associates, 1993). For some, the inability to receive care occurs, as noted earlier, because they are unable to pay for services; the highest percentage of those reporting difficulties in meeting needs came from those who were severely impaired, living alone, or poor or near-poor (Feder, Komisar, and Niefeld, 2000). For some, the increasing unavailability of Medicaid nursing beds creates a no-care zone.[27] In some areas, the demand for services exceeds resources. In 1990, the National Association

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[26] Predicting adequate coverage for the near poor is made even more difficult because states, historically, have differed in their generosity of Medicaid benefits.

[27] Because Medicaid reimburses nursing homes at a lower rate than Medicare, nursing homes have reduced the number of Medicaid beds available. This problem is discussed in more detail in Chapter Four.

of Area Agencies on Aging (AAA) conducted a survey of member organizations to determine the level of unmet needs among older persons. Eighty-three percent of the AAAs said that their constituents were unable to meet needs for personal care, 84 percent were unable to meet the need for home-delivered meals, and 85 percent were unable to meet the demand for transportation services (National Association of Area Agencies on Aging, 1990).

Bishop (1999) calls attention to the "missing elders" in her tracking of demographic shifts in long-term care use. About 250,000 fewer elderly people, similar in terms of age and gender, lived in nursing homes in 1995 than in 1985 (4.2 percent of the population in contrast to 4.6 percent of the population, reflecting an 8.2 percent decline). Some, but not all of this decline, Bishop suggests, might be due to declining disability rates among the elderly. More likely, given increases in the number of informal and unpaid hours of care during that decade, family and friends account for some of the difference. And, given declines in the private-pay portion of nursing home budgets, it is likely that some of these elders are purchasing the care they need through home care or living in private-pay assisted living facilities. It may also be that some of these elders are falling through the cracks and receiving little or no care because of inability to purchase services (Bishop, 1999).

Fourth, a lack of fit between funded services and what frail elders seem to need exists.[28] This is evident in payment systems, service provision, and service delivery systems. In terms of payment systems, Medicare primarily is a catastrophic

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[28] The use of the word "seem" is intentional. We do not have a wealth of data on what it is that elders perceive to be needed in terms of long-term care. Based on existing data, some observations can be made.

health insurance program, focused upon the diagnosis and treatment of disease. It is organized around discrete, disconnected service events that happened in the past. As a reactive, episodic model, Whitelaw and Warden (1999) argue that it is inappropriate for its beneficiaries, 88 percent of whom have at least one chronic condition. The primary challenges in geriatric medicine today- -the management of multiple chronic diseases, the prevention of functional declines, and the promotion of successful aging- -is not what Medicare is primarily about (Cassell, Besdine, and Siegel, 1999). Similarly, Medicaid is intended to meet the needs of the poor or near-poor for catastrophic health care insurance. It has become, as suggested earlier, the primary payer for nursing care. While not all poor people in need of long-term care need nursing home care, many are forced into premature institutionalization because this is their only option for care. About 20 percent of all placements in nursing homes are judged to be inappropriate or preventable (American Association of Retired Persons, 1997; Kane, Kane, and Ladd, 1998).

The mismatch between funded services and what elders seem to need is also apparent when looking at elders' preferences for receiving long-term care in contrast to allocations for long-term care. In general, the literature suggests that many elders strongly prefer home and community-based care over nursing home care (Cetron, 1985; Estes, Swan, and Associates, 1993; McAuley and Blieszner, 1985; Rivlin and Wiener, 1988). A national study of more than 3,000 seriously ill hospitalized elderly patients were polled to determine how willing they would be to live permanently in a nursing home. Twenty-six percent indicated that they would be very unwilling to live permanently in a nursing home, 30 percent said they would prefer death over a nursing home placement, and only 7 percent stated that they would be very willing to live permanently in a nursing home (Mattimore, Wenger, et al. 1997). In spite of this preference, two-thirds of long-term care spending is allocated for nursing home care.

The mismatch is further apparent within nursing homes in terms of services available or not available to residents. Within nursing homes, the very old (i.e., aged 80 and older) often recognize the futile nature of expensive, hospital-based services and prefer that health care resources be allocated instead to maintain function and independence in the home (Lynn, 1996; O'Connor and Lynn, 1995). In spite of this, for the very old, Medicare hospital expenditures are high: one-third of Medicare's reimbursements in 1994 were used by persons aged 80 or older, who constitute 24 percent of the population. Acute changes in health status of nursing home residents leads to expensive transfers to hospitals where complications frequently occur. It is estimated that more than $1 billion dollars are spent annually in the United States on avoidable care for nursing home residents (Joseph and Boult, 1998). In another study, a conservative estimate suggests that 36 percent of the transfers from skilled nursing facilities to the hospital emergency department and 40 percent of hospital admissions were inappropriate (meaning that the patient safely could have been cared for at a lower level of care); in fact, 27 percent of these transfers resulted in death (Saliba, Kington, et al., 2000).[29] Inappropriate hospitalization of nursing facility

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[29] The impetus for transfers comes through financial incentives to hospitals and physicians for the volume of acute care services provided. Physicians are paid for services delivered in the hospital but not in nursing homes under most fee-for service plans. Furthermore, hospitals benefit by transfers if they have open beds and can admit and discharge patients within DRG rules for length of stay. Nursing homes benefit because they may not have the needed reimbursable acute care services in the facility (Ouslander, Weinberg, and Phillips, 2000; Saliba, Kingston et al. 2000).

residents "is a symptom of a much more costly and critical problem in our health care system. We must work together to develop more integrated systems of care for frail older people. These systems must have properly aligned financial incentives and respect for the preferences and quality of life of this population" (Ouslander, Weinberg, and Phillips, 2000, p. 231).

Within home care, an incongruence is noted between the categories of care[30] which more accurately reflect real needs in contrast to the broad types of care, skilled nursing care in the home through Medicare or nursing home care through Medicaid, created by payment programs. Furthermore, the latter prioritize medical over personal and social needs of frail elders, a prioritization not necessarily preferred by frail elders. In measuring the goals of frail elders for long-term care, Bradly, Bogardus, et. al. (2000) argue that elders' goals are very general and fundamental- -to maintain health and well-being, current functioning, and independence. Similarly, Lynn, O'Connor, et. al. (1999) find that among their focus group participants, 74 percent of persons over the age of 80 are in favor of an alternative healthcare benefit (called MediCaring) that would emphasize more home-based and supportive health care and discourage the use of hospitalization and aggressive treatment; 34 percent indicate a willingness to accept such a benefit immediately if it were offered. Wallace (1990), a decade earlier, found that the provision of supportive and basic needs to frail elders were cited as being most important to preventing institutionalization. In spite of this, community-based services continue to shift to

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[30] These categories of include personal care (assistance with ADLs), housekeeping and chore services (assistance with IADLs), routine nursing and health maintenance,

more medical orientations as a result of budget constraints and as a mechanism to contain growing budgets (Greene, Ondrich, and Laditka (1998). Wallace (1990) finds it "is ironic that government programs support a clean, safe, heated home for the disabled elderly only when the home is a nursing home" (p. 260).[31]

Fifth, concerns about formal and informal care-givers abound, particularly in terms of an available work force and the emotional and financial costs incurred.[32] Families are the major long-term care providers; unpaid care-givers are generally women who provide care to a loved one in the home.[33] Seventy-five percent of primary care-givers are women, 36 percent are adult children, and 40 percent are spouses. Relatives and friends often assume the role of secondary care-givers, filling

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supervision for safety (as with cognitively impaired persons), rehabilitation, and management.

[31] Medical needs are prioritized over social needs in nursing homes as well through reimbursement policies that compensate medical and surgical procedures more generously than cognitive services (providing information and education, offering support, linking clients to resources) (Scott, Aiken, Mechanic, and Moravcisk, 1995).

[32] Care-givers refers to both informal, or unpaid, care-givers, and formal, or paid, care-givers. Both groups are increasingly referred to as "careworkers" in the empirical literature to emphasize that care is not free in terms of economic or emotional costs, and to emphasize that good care is hard work (Meyer, 2000). The term 'careworker,' however, is used mostly by academics; formal and informal care-givers seldom refer to themselves with this term.

[33] The significance of an informal care network is evidenced by the fact that 50 percent of elderly persons with long-term care needs who lack family arrangements live in nursing homes, compared to only seven percent of those who have family care-givers (R. Stone, p. 12). Estes, Swan, and Associates (1993) conclude that the significant factor in keeping frail elders out of institutional settings is not the elder's degree of functional impairment but rather the level of access to family care and social support, and more specifically, the availability of adult daughters (Estes, Swan, and Associates, 1993). Henderson (1995) suggests that most nursing home placements are made due to lack of adequate community resources. These claims, however are challenged by Tennstedt, Chang, and Delgado (1998) who find that the extent of disability, not the availability of informal care, is the most consistent correlate of the likelihood of receiving certain amounts of care. Choi (1999)

in when spouses and children need respite (R. Stone, 2000). According to the National Alliance for Care-giving survey (NAC), the average care-giver is a 46-year old employed woman caring for her 77-year old mother who lives nearby and for whom care has been provided for the past four years (1997).[34] Other studies indicate that 30 to 50 percent of primary informal care-givers are women over the age of 65 (Doty, Jackson, and Crown, 1998; Weinberg, 1999). It is estimated that in 1997, 25.8 million unpaid care-givers delivered an average of 17.9 care-giving hours per week (Arno, Levine, and Memmott, 1997). As the level of disability increases, hours of care-giving increase; such estimates have included 52.5 to 58.8 hours per week for Alzheimer's disease patients, 70 hours per week for ventilator dependent patients, and 22 hours per week for Parkinson's disease patients. On average, care-giving for elders lasted eight years, with a range of care from 3 to 15 years (Timmermann, 2000).

The financial and emotional costs involved in unpaid caregiving are substantive. Although a sense of satisfaction at being able to meet needs and increased affection for each other are cited as positive outcomes in care-giving, such satisfactions are tempered by a number of stressors. These include marital strains, learning to deal with changed relationships between care-giver and receiver, responding to the affective states of care receivers, and needing to learn how to deliver personal care and attend to medical-technical skills relationships.

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concluded that need and race (being white) are the most significant determinants of nursing home placement.

[34] The NAC survey (1997) found that 40 percent of its estimated 22.4 million care-givers for persons over the age of 60 also cared for children under the age of 18.

Additionally, care-givers report restrictions on their own time and activities (Bowman, Mukherjee, and Fortinsky, 1998; Hooyman and Gonyca, 1995; Kane, Reinardy, Penrod, and Huck, 1999).

In terms of paid employment, Pavalko and Artis (1997) find that employed women are not less likely to start care-giving when the need arises; rather initiating care-giving is equally likely for all women. Employed women, once they begin care-giving for an elder, are more likely to reduce or stop employment. Of the 31 percent of primary care-givers who do hold paying jobs, nearly 67 percent work fulltime, and invest, on average, 18 hours per week in addition to arranging help from other informal and formal care-givers to supplement their efforts.[35] Employed primary care-givers who care for severely disabled elders (i.e., those with three or more ADL limitations) provide between 32 and 39 hours of care per week (ASPE and AoA, 1998; Stone, R., 2000) This paid work is altered to accommodate their care work responsibilities. Such accommodations include taking leaves of absence, turning down promotions, assuming less challenging positions, reducing the number of hours worked, and sometimes leaving paid employment permanently. Such accommodations translate into lost wages, health and pension benefits, and Social Security benefits (Timmermann, 2000).[36] When care-giving occurs in the years just

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[35] Part-time employed workers provide, on average, about 21 hours per week of care (Doty, Jackson, and Crown,1998).

[36] In 1999, the MetLife Mature Market Institute, in conjunction with the National Center on Women and Aging at Brandeis University, completed a pilot study (n = 55) using a subset of the 1997 NAC/AARP study (National Alliance for Care-giving, 1997). This was not a representative sample; rather it provided a more detailed and complete accounting of losses and tensions faced by care-givers. By aggregating lost wages over the lifetime ($566,000), lost Social Security benefits ($25,000), and lost pension wealth ($67,000), the care-giver's loss average over the lifetime was

prior to retirement eligibility, exits from the labor force or reductions in hours significantly affects long-term income, reducing Social Security and/or pension benefits (Kingson and O'Grady-LeShane, 1993). From the employer's perspective, $11.4 to $29 billion dollars (1997 dollars) is lost annually to care-giving in lost productivity (Metropolitan Life Insurance Company, 1997).

Paraprofessional workers, after informal care providers, deliver the largest share of long-term care. According to the Bureau of Labor Statistics (1999), about 643,000 nursing assistants were employed in nursing homes in 1998. The number of home care assistants is more difficult to determine because many aides are hired privately; the Bureau of Labor Statistics estimates that about 697,000 home health aides were employed by home health agencies in 1998 (2000-2001). These workers provide 90 percent of direct care in nursing homes and 80 percent of the formal direct care in home care (R. Stone, 2000). These workers are primarily women of color, often immigrant women, disenfranchised by race, class, gender, and, increasingly, citizenship.

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estimated to be $659,000. Care-givers also assisted with out-of-pocket expenses; the average lifetime expense was estimated at $19,500. Respondents further noted limitations and reductions in savings, investments, buying a car, affording college tuition for children, etc. Care-giving also took a toll on respondents' health; three-fourths said that care-giving affected health poorly, and two in ten reported significant health problems correlated with care-giving. Finally, care-givers reported on employment adjustments. Two-thirds of the respondents also worked in the paid labor force. Almost all had made informal adjustments to their work schedules; 84 percent made formal adjustments to work schedule to accommodate caregivng responsibilities. Two-thirds had used work or sick days, decreased hours, took leaves, or quit altogether. Forty percent of the respondents said care-giving had affected their ability to advance via promotions (Metropolitan Life Insurance Company, 1999). Gerbman (2000) estimated lost wages, benefits, and Social Security for care-givers providing more than eight hours of care per week at upwards of $695,000 over their lifetimes.

As with informal care-givers, the financial and emotional costs of such carework for paraprofessionals are exacting. They are among the worst paid service sector workers, with 30 percent having an average median income of $9000 or less and no health or pension plan benefits.[37] The rate of injuries and illness resulting in loss of paid work days is among the highest of all service category workers. Racial tensions abound. Nursing and home health aides cite lack of respect and autonomy, lack of career advancement, intensity of common human interactions with little control over outcomes, and lack of extrinsic rewards as additional stressors (Banaszak-Holl and Hines, 1996; Stone, R., 2000). High turnover rates reflect concerns about low wages and high demands. Within nursing homes, the turnover rates often exceeds 75 percent in a six-month period (Banaszak-Holl and Hines, 1996).

The shortage of paraprofessionals in nursing and home care is even more severe than the geriatrician shortage and demands are expected to increase; as an occupation, home health care aides is the fourth fastest growing sector (Bureau of Labor Statistics, 1998). The demand for home care workers is predicted to increase due to the aging of the population, increased reliance on home care over acute care and other forms of institutional care, expanded home care coverage through Medicare

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[37] The median hourly rate for nursing assistants in 1998 was $7.99; $7.58 for personal care attendants or home care aides (Bureau of Labor Statistics, 2000-2001). Forty-three percent of nursing home aides and 14 percent of home care workers received health insurance through their employers; 36 percent of nursing home aides and 25 percent of home care workers received some type of employer pension plan (Crown, Ahlburg, and MacAdam, 1995). Many home care workers were considered to be independent contractors, which means that employers do not provide health or retirement benefits, or Social Security contributions (Weinberg, 1999).

and Medicaid, and preferences to remain in the home (R. Stone, 2000). Nursing aide demand will also continue to increase because of continued pressure to use sites other than acute care settings, and continued efforts at more seamless systems of care between health and long-term care settings. The availability of these future workers is a serious concern. The educational status of African American women, who currently constitute a large portion of the service sector, is improving and in the future, they will be less likely to work in low-wage service jobs (U.S. Bureau of the Census, 1998).[38] A high proportion of careworkers are immigrant women, particularly in states with high immigrant populations, such as California, New York, Texas, Florida, and New Jersey. Although data on paraprofessionals are not classified by immigrant status, a high proportion of care workers are people of color. Forty percent of all immigrants are in two occupational sectors, operator/laborer and service worker. They come to the United States to rejoin their families, and not necessarily for high-skilled employment. Thus they comprise a ready labor pool for paraprofessional jobs in long-term care. Policies to limit immigration may well diminish this labor pool as well.[39]

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[38] In 1980, 51.3 percent of black women had high school educations; 8.1 percent had graduated from college. In 1998, 76.7 percent had graduated from high school; 15.4 percent had completed at four or more years of college.

[39] The focus here is on those who do the hands-on work of care. While physicians, nurses, and social workers are often removed from the day-to-day work of care-giving, they are nevertheless key to good care. Physicians, while not delivering long-term care services, provide the sanction for receiving such services, make referrals, and work with worried family members who are primary care-givers. Their role is important, yet few are trained for it. Only 1.2 percent of the 684,000 physicians in the U.S. are certified in geriatric medicine (Larson, 1998). Current estimates suggest we need about 20,000 geriatricians (a shortage of 13,000 geriatricians); this number will increase to nearly 37,000 by 2030. Of the 98,000 medical residencies and fellowships supported by Medicare in 1998, only 324 of these were in geriatric care

A final overarching concern in long-term care is that of quality of care. Within nursing homes, in spite of the OBRA 1987 regulations, about one-fourth of the more than 19,000 nursing homes have serious deficiencies in their care and about 40 percent of these homes had repeat deficiencies (Feder, Komisar, and Niefelds, 2000). The Minimum Data Set (MDS) came out of the 1987 OBRA regulations and was seen as an attempt to collect a uniform set of information on every nursing home resident at regular intervals from admission to discharge/death. It was intended to inform individualized care planning and outcomes tracking.[40] The Institute of Medicine, whose report was influential in shaping the 1987 OBRA regulations, saw uniform resident assessment as a foundation upon which to improve quality in nursing home

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(Besdine, 1994; Stone, R., 2000). Nurses provide the majority of professional long-term care. Eight percent of all registered nurses (n = 170,856) work in nursing homes or extended care facilities; an additional 129,304 registered nurses work in home health care settings in 1998 (www.nahc.org/Consumer/hcstats.html) . In addition, about 182,000 licensed practical nurses work in nursing home settings and nearly 40,000 work in home health care. The majority of registered nurses in long-term care serve in administrative roles as head nurse or director of nursing, and along with physicians, plan and assess treatment plans. Licensed practical nurses supervise nursing assistants, distribute medications, do treatments, and monitor the conditions of patients. About 6000 social workers (full-time equivalents) are represented in home health care, a small segment of home health workers. In nursing home care, under OBRA 1987, facilities with more than 120 beds are required to employ a full-time "qualified" social worker; a qualified social worker is defined as someone with a BSW or a BA in a human services field, the latter degree raising significant questions about meeting the minimal requirements for a "qualified" social worker (Tirrito, 1996). Labor force projections of demand for gerontologically trained social workers is projected to reach 60,000-70,000 within the next 20 years (Greene, Barush, and Connelly, 1990).

[40] Three categories of information about quality of care - - structure, process, and outcome - - are commonly collected. In theory, the first two are related to the third, in that appropriate structures and processes are thought to lead to better outcomes; this linkage, however, is not consistently demonstrated empirically. Historically, the focus of evaluation has been on structure and process, not upon outcomes, and particularly, not upon good outcomes ("bad" outcomes are easier to document).

care.[41] They asserted that "providing high quality of care requires careful assessment of each resident's functional, medical, mental, and psychological status upon admission, and reassessment periodically thereafter, with change in status noted. . . . [The] development of individual plans of care clearly depends on resident assessments" (Morris, Hawes, et. al, 1990, p. 294). These goals, however, have not been met. The MDS is seen by some as another regulatory device imposed from without. While data is collected (sometimes by external data collectors, ironically), it has not been used to inform case planning (Kane, 1998).[42] Few nursing homes have utilized the MDS as a mechanism to enrich their understanding of residents; the developing relationship is secondary to the task of completing the paperwork.

Problems within nursing homes as quality places to live are informed by limited, albeit rich, ethnographic studies and by numerous studies within the empirical literature.[43, 44] From such studies we learn that residents' lives in their totality are shaped by rigid routines designed for staff and operational efficiency. This routinized life is lived largely in public view and crowded spaces within the institution. Communication with those outside of the facility can be difficult to arrange, particularly if one has to depend on someone else to place a phone call or

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[41] The Institute of Medicine (IOM) falls under the purview of the National Academy of Sciences, created by the federal government to be an adviser on scientific and technological matters. The Academy, however, and its associated organizations (e.g., the IOM) are private, non-governmental, organizations and do not receive direct federal appropriations for their work. Studies undertaken for the government by the Academy usually are funded out of appropriations made available to federal agencies.

[42] Quality of care issues are also present at the level of individual care for nursing home residents. These are discussed more fully later.

[43] For ethnographic studies, see, for instance, Diamond (1992), Foner (1994), Gubrium (1975, 1993), and Schmidt (1990).

[44] Quality of care concerns, in particular, are developed in more detail later.

write a letter. The nursing home rules and regulations are designed for those residents most impaired, with insufficient regard for those who are cognitively alert. Maintaining a sense of personal identity (Tobin, 1991) and exercising control and choice over everyday matters (Kane, Caplan, et al. 1997) is difficult; these basic activities are often trumped by issues of safety, efficiency, and the medicalization of care in nursing homes.

Widespread documentation exists of deficiencies in the personal care of nursing home residents. Residents suffer from infections, pressure ulcers, and poor management of chronic illness because "the causes of such ineffectiveness and inefficiency stem from perverse financial incentives that discourage geriatric clinicians from practicing in nursing homes, deter nursing homes from developing subacute care capacity, and reward transfers to acute care hospitals" (Boult, 1999, p. 250). Kayser- Jones, Schell, et al. (1999), in an ongoing longitudinal study of life within nursing homes, found that dehydration is the most common fluid and electrolyte disorder in nursing and home care; 62.5 percent of the residents had illness or conditions related to dehydration.[45] Even though a complex interaction of clinical, sociocultural, and institutional factors contribute to this problem, the authors argue that " providing people with an adequate amount of fluid is a basic, universal physiological need. It is not sophisticated, highly technological, costly care. If we do not provide an adequate amount of fluid to nursing home residents, we have seriously

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[45] In 1996, 208,000 elders were admitted to acute-care hospitals in 1996 with a primary diagnosis of dehydration; the cost of hospitalization for dehydration was $1.36 billion (based upon 6.5 days average length of stay at $1006 per day).

failed our older citizens" (p. 1193).[46] Additionally, as part of the same longitudinal study, Burger, Kayser-Jones, and Bell (2000) found that 35 to 85 percent of U. S. nursing home residents are malnourished. These malnutrition and dehydration rates are similar, suggest the authors, to those found in poverty-stricken developing countries.

While we know a great deal about the quality of care (or lack thereof) within nursing homes, understanding and assuring quality of care in the home has only begun and is complicated by several factors. This is an arena which historically has been private and off-limits to government regulation; subsequently, abuse or neglect is difficult to document and remedy (Feder, Komisar, and Niefeld, 2000). The recipients of care are very vulnerable and potentially isolated; they may have few options other than nursing home care, and thus are reluctant to express any problems. Furthermore, much of the care-giving is provided by family members or friends, who may not have the requisite training and support (Binstock, Cluff, and von Meyering, 1996). The physical dimensions of the home, with stairs, inaccessible cupboards, or lack of assistive devices for lifting and bathing, furthers risk to frail elders and may

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[46] Clinical factors include inaccurate assessment and/or communication of dysphagia (swallowing disorders) to nursing assistants who unknowingly feed residents lying on their sides, functional impairments preventing residents from taking liquids independently, cognitive impairments such that residents are unable to ask for liquids, and poor pain management. Sociocultural factors include residents without family or friends to assist them in drinking, language barriers, serving beverages not liked by residents, and beliefs and practices of staff to speed up the feeding process which residents then rejected. Institutional factors include lack of trained staff to feed residents, lack of supervision of nursing assistants, and inaccessible liquids (placed out of reach to prevent drinking from one another's glass) (Kayser-Jones, Schell, et. al. 1999).

compromise existing autonomy. Settings are less supervised, raising concerns not only (or even primarily) about abuse by family members or home care workers to frail elders but neglect or forgetfulness of self-care by the elder in such areas as taking medications (Aulisio, May, and Aulisio, 1998). Finally, information regarding services and outcomes is limited. Board-and-care homes, along with assisted living facilities, often fall outside of state regulatory systems (Feder, Komisar, and Niefeld, 2000).

These widely recognized and documented concerns in long-term care are often described in technical, medical, and monetary language. More efficient systems of long-term care, purged of financial waste and fraud, and informed by precise diagnostic categories, are held forth as holding promise for solving problems of long-term care. While such resources are certainly required, the concerns of long-term care briefly noted here are not, at their core, technical problems requiring a technical fix. Rather, such concerns point to more foundational moral and ethical questions that need to be addressed. These concerns, understood through a public ethic of care, raise different kinds of questions and point to different solutions.

This chapter, in summary, sets the stage for further development of a public ethic of care in the long-term care arena. Several areas that need further development in subsequent chapters have been introduced, including the aims of this dissertation, the notion of an ethic of care, and an overview of long-term care in the United States.

PART ONE
AN ETHIC OF CARE AND AN ETHIC OF JUSTICE: A REVIEW OF THE LITERATURE

Chapter Two
Philosophical and Historical Antecedents of an Ethic of Care

This chapter provides a foundation for further discussion of a public ethic of care in long-term care by reviewing the philosophical and historical antecedents that frame the debate between an ethic of care and an ethic of justice. The objective is to locate and understand this debate within a broader historical and philosophical context, which includes the development of the social work profession. This is important to do for several reasons. First, in locating the debate in a larger context, the emergence of some of the limiting and artificial dichotomies that appear between an ethic of justice and an ethic of care become more clear and thus open to critical analysis. Second, the "baggage" that for some accompanies an ethic of care can be clarified and care's legitimacy as a central moral value can be considered. Third, by including a consideration of how the social work profession has been influenced by some of the historical and philosophical antecedents to the care – justice debate, social workers can better recognize the limiting context out of which the profession emerged in the late 1800s, and consider whether a public ethic of care is useful for defining and framing the profession in this century.

This task is accomplished by first reviewing the Kohlberg – Gilligan debate, the modern day impetus for continued discussion of an ethic of care. Second, the Western philosophical antecedents of an ethic of care and an ethic of justice within the moral traditions of Sentiment and Reason, respectively, are identified. Third, the historical antecedents for the notion of women's morality, a concept re-visited with

Gilligan's work and critiqued with new vigor, is reviewed. The focus on historical antecedents of the ideas of women's morality, however, is limited to a discussion of that history as it shapes and influences the development of the social work profession.[1] Thus the time period considered most carefully is the nineteenth and early twentieth centuries.

The Kohlberg – Gilligan Debate

Gilligan's work is located within cultural feminism. In contrast to liberal, radical, or Marxist feminist thought, which explain women's oppression in terms of political and economic societal structures or in terms of sexual and reproductive practices, cultural feminism argues that there may be biological, psychological, and/or cultural explanations for the differences between the moral values traditionally associated with men and women. Cultural feminists argue that boys and girls grow into men and women with gender-specific virtues that reflect the importance of separateness in the lives of men and connectedness in the lives of women. These values serve to empower men while oppressing women.

<u>Kohlberg's Ethic of Justice</u>: Gilligan's work and its contrast to Kohlberg's work have been described and critiqued extensively elsewhere. To summarize, Kohlberg attempted to explain the process of moral reasoning (1981 - 1984). Based on the responses of his subjects to the Heinz dilemma,[2] Kohlberg divided moral

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[1] A discussion of this history in its entirety is beyond the intent of this chapter. Connections between social work and the idea of women's morality, however, given the link of this dissertation to social work, are interesting to note.

[2] The original dilemma is as follows: In Europe, a woman was near death from cancer. One drug might save her, a form of radium that a druggist in the same town had recently discovered. The druggist was charging $2000, ten times what the drug cost him to make. The sick woman's husband, Heinz, went to everyone he knew to

reasoning into three main levels with two stages within each level. At level one, preconventional morality, children reason in terms of their own welfare and judgments are based on external sources of authority who are close by and physically superior - - usually parents. In stage one of this level (punishment and obedience orientation), children rely on the physical consequences of some action to decide if the action is right or wrong. If the child is punished, the action is wrong; if the child is not punished, the action is right. The most important value is obedience to authority in order to avoid punishment. In level two (individualism, instrumental purpose, and exchange), children follow the rules when it is in their immediate interests to do so. Actions that bring pleasant results are good actions. Some beginning concern for other people is apparent but this concern is generally expressed as something that benefits the child as well.

At the conventional level, individuals consider social standards and laws to be the primary source of moral values. The young person shifts from judgments based on external consequences and personal gain to judgments based on rules or norms of the group to which one belongs. What the chosen reference group defines as right or good *is* right or good, and the individual begins to internalize these norms. In stage three (interpersonally normative conformity or good boy/nice girl stage), individuals consider good behavior to be that which pleases other people. They value trust, loyalty, respect, gratitude, and maintenance of mutual relationships. The young

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borrow the money, but he could only get together about half of what it cost. He told the druggist that his wife was dying and asked him to sell it cheaper or let him pay later. But the druggist said, "No." The husband got desperate and broke into the man's store to steal the drug for his wife. Should the husband have done that? Why? (Kohlberg, 1969, p. 379).

person makes judgments based on intentions as well as outward behavior; thus if someone "means well," their wrongdoing is seen as less serious than if it were done with intention. During stage four (social system and conscience), the conformity of stage three is shored up by a recognition of the value of maintaining the social order and of the contribution of dutiful behavior to that order. Right behavior means being a dutiful citizen, respecting authority, and obeying the laws set down by society. The laws themselves are not yet questioned.

At Kohlberg's post-conventional stage, individuals follow moral principles that may supersede the standards of society or the wishes of the individual. In stage five (social contract), individuals continue to value rules, laws, and regulations because they ensure fairness and are endorsed by society as a whole. If rules become destructive, however, or if parties do not honor their commitments, contracts are no longer binding and individuals may ignore or change the rules. Ultimately, at stage six (universal ethical principles), individuals think in terms of self-chosen but universal principles such as justice and basic respect for persons. These values are established by reason and reflection, and may contradict the egocentric or legal principles of earlier reasoning.

Kohlberg argues that his stages are cognitive (that is, they depend upon intellectual skills for further development), sequential (that is, one must proceed through the stages in the order indicated), universal (applicable to all persons), and hierarchical (that is, those at lower stages have lower moral sensibilities than those at the higher stages). The key intellectual skill needed to move to a higher level is the skill of reciprocity where one is able to put oneself into the place of the other person in the dilemma. Individuals at stage six, for instance, will behave morally because they have been able to see all sides of the issue through idealized role-taking. They have what Seyla Benhabib has called the capacity of the self to become "the generalized other" (1987, p. 163).[3]

Gilligan criticizes Kohlberg's work on methodological and substantive grounds. Methodologically, Kohlberg's initial group of subjects included only males, thereby yielding incomplete and biased results. In later studies, girls and women tested using Kohlberg's scale rarely moved beyond stage three. Kohlberg writes:

> While girls are moving from high school or college to motherhood, sizeable proportions of them are remaining at Stage 3, while their male age mates are dropping Stage 3 in favor of the stages above it. Stage 3 personal concordance morality is a functional morality for housewives and mothers; it is not for businessmen and professionals (Kohlberg and Kramer, 1969, p. 108).

Gilligan argues that remaining at stage three was not because girls and women are less moral than boys and men but because Kohlberg mistakenly constructed a scale to measure men's methods of moral reasoning. Gilligan also criticizes

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[3] Benhabib borrows this term from George H. Mead although she defines it in the tradition of social contract theorists, that is, with an abstractly defined, legal and juridical subject. The standpoint of Benhabib's generalized other is grounded in an understanding of the other as a rational being entitled to the same rights we would choose for ourselves. The norms of equality and reciprocity govern interactions; these norms are usually public and institutional. The moral categories accompanying such interactions are those of right, obligation, and entitlement. Mead, in contrast, used this term to describe the social and psychological construction of an individual; being able to take on the norms, values, attitudes, and expectations of people or groups of people "in general" - - the generalized other - -is a significant step in the development of a self (Mead, 1934, 1955).

Kohlberg's use of hypothetical moral conflicts as the correct way in which to understand moral conflicts. In order to understand how people think about moral and ethical issues, Gilligan argues that one needs to work with actual moral dilemmas experienced by one's subjects.

Gilligan's Ethic of Care: Responding to what she interpreted as Kohlberg's flawed methodology, Gilligan conducted an empirical study of twenty-nine pregnant women, all of whom were deciding whether to have an abortion or carry the fetus to term.[4] Gilligan concluded that regardless of various demographic variables, these women portrayed a style of reasoning markedly different from the men who had been tested by Kohlberg's scale. Rather than approaching their abortion decision as if it were a math problem about whose rights weigh more, Gilligan's subjects approached the decision as a human relations conflict, determining how various outcomes would affect themselves, their fetus, their families, and their partners.

To describe the development of this moral orientation, Gilligan proposes three levels and two transition periods in forming her ethic of care. At level one (orientation to individual survival), survival of the self is the sole object of concern. Moral considerations emerge only when one's own needs are in conflict. In transitioning from selfishness to responsibility, women recognize the attachments and connections they have with others. Their own wishes and responsibilities are viewed as the context of conflict between what one "would" and "should" do. At the second level (goodness as self-sacrifice), concern for others, particularly the feelings of others and the possibility of inflicting hurt, is a major theme. Goodness or self-

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[4] This summary is from Gilligan (1982).

sacrifice and the need for approval is joined with the desire to care for and protect others. The second transition from goodness to truth involves recognizing that a morality of care must include care of oneself as well as others. In this transition, a woman strives "to encompass the needs of both self and others, to be responsible to others and thus be 'good' but also to be responsible to herself and thus to be 'honest' and 'real'" (Gilligan, 1977, p. 500). A heightened sense of responsibility for decisions made accompanics this transition. At level three (the morality of nonviolence), conflicts between selfishness and responsibilities to oneself and others are resolved in a principle of non-violence. Moral equality is achieved by applying an injunction against harming either oneself or others

Gilligan's findings led her to also criticize Kohlberg's work on substantive grounds. No account of morality is complete, asserted Gilligan, if it only includes questions of justice (what Kohlberg later called a morality of justice). Gilligan argued for the existence of a different moral voice, one more often heard in the experiences of women. This voice emphasizes the preservation and nurturance of human relationships. Gilligan writes:

> In this conception, the moral problem arises from conflicting responsibilities rather than from competing rights and requires for its resolution a mode of thinking that is contextual and narrative rather than formal and abstract. This conception of morality as concerned with the activity of care centers moral development around the understanding of responsibility and relationships, just as the conception of morality as fairness ties moral development to the understanding of rights and rules (1982, p. 19).

Critique of Gilligan's work: Gilligan names the contrast she identified as an ethic of care versus Kohlberg's ethic of justice. Her work is controversial and the implications of her work have reverberated throughout academic and non-academic spheres. Here, three major criticisms of her work are identified, not with the goal of critically revisiting her work and the scholarship devoted particularly to her work, but with an eye toward understanding how Gilligan's work has influenced further development of an ethic of care.[5]

One major criticism of Gilligan's work is that she overstates the uniqueness in distinctions between an ethic of care and an ethic of justice. Some critics note that Gilligan is not the first person to posit differences in approaches to morality, nor the first person to gender-load such differences. As noted earlier, this discussion has a long and rich tradition within moral theory. Ethicist William Frankena suggests that "there are two basic principles of prima facia obligation: that of benevolence and that of justice or equality" (p. 1963, p. 42). George Sher, drawing upon traditional ethicists such as Kant and Schopenhauer, argues that Gilligan's distinctions "are not recent empirical discoveries but generic determinants of the moral problematic" (1987, p. 187).

Other critics (in regards to the first large criticism of Gilligan's work) suggest that care and justice are not unique, dichotomous approaches to moral reasoning but complementary approaches. Some critics, such as Kohlberg, subsume Gilligan's account of morality into a justice account, thus making it complementary to justice

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[5] Critically revisiting Gilligan's work and the scholarship devoted to it is not the task of this project. For a useful collection of papers illustrating the influence of Gilligan's work see Kittay and Meyers (1989) and Sunstein (1990).

rather than distinct from justice (Tronto, 1994). Other critics explore the relationship between care and justice in private contexts, and argue convincingly that justice is needed to inform care (Friedman, 1987; Okin, 1989; O'Neill, 1989; Shrage, 1994).[6] Gilligan attempts to articulate the nature of the interactions between care and justice with her gestalt analogy (1987).[7] Unlike those who argue that justice has a place in intimate relationships, however, Gilligan only concludes that both ethics must play a part in public and private life; she does not explore such applications (1986).[8, 9]

A second major criticism of Gilligan's work is her connection of an ethic of care to gender. Several threads of critique are found here also. First, some, like Michelle Moody-Adams (1991), believe that Gilligan not only privileges an ethic of care over an ethic of justice but her attempts to empirically link an ethic of care with women leads to the conclusion that Gilligan believes women are more moral than men. This tends toward biologism, and such a link of genetics to biology is dangerous. Moody-Adam inquires whether Gilligan, who notes the overwhelming percentage of males in comparison to females in prison as an example of sex

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[6] Arguments in the other direction, that care is needed to inform justice, are underdeveloped; thus the impetus for this project.

[7] Gilligan's gestalt analogy is grounded in ambiguous figure perceptions where, depending on how one looks at a picture, one can see either (for instance) a duck or a rabbit emerge as dominant. Perhaps the relationship between justice and care is similar to this, suggests Gilligan.

[8] Nel Noddings, also an eminent defender of an ethic of care, suggests that an ethic of care has applications to the public sphere but fails to specify how this might occur. Noddings, while arguing that caring is an alternative to justice, acknowledges that she "is not yet ready to say exactly how justice and care should be combined" (1990, p. 120).

[9] The precise relationship between care and justice as understood in this dissertation is discussed more extensively in Chapter Three.

differences in immoral and moral behavior, would be equally eager to ascribe the higher percentage of African Americans to whites in prison as connected to higher levels of morality for whites than blacks.

Furthermore, attempts to link caring as something natural to women, as something essential to their being, is ultimately disempowering to, if not oppressive for women. The inclination of women to care can quickly veer into passivity, lack of autonomy, and self-denial of their humanity. Feminists such as Claudia Card and Catherine MacKinnon, are deeply suspicious of the validity of women's instincts of care. They argue that such instincts are constructs of women's subordination, shaped by social norms and formed under conditions of injustice, that frequently work against women and serve male interests. To Gilligan's claim that women speak in a different voice of care, MacKinnon responds skeptically: "If you will take your foot off our necks, then you will hear in what voice women speak" (1987, p. 45).[10] Kroeger-Mapes (1994) suggests that while Gilligan's work is important because it asks how girls and women fit into traditional ethical theory, it is nevertheless a feminine ethic that is consistent with women's subordination. Just as an ethic of rights is falsely generalized to women as well as men, argues Kroeger-Mapes, Gilligan's "modified official story" is another false generalization that a different voice of moral reasoning belongs to women. As such, she does nothing "to significantly alter or transform the official story" (p. 109). Finally, Frye (1983) reminds that the different voice Gilligan claims to have uncovered, regardless of

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[10] For further discussion of this criticism of Gilligan's work, see such writers as Bartky, 1990 and Houston, 1988.

whether it reflects cultural expectations for women or reveals something distinctively instinctual to women's moral reasoning, reflects only the voices of some women - - those who are white and well-educated- -while ignoring differences in race, class, and culture.

Other critics, perhaps more charitable to Gilligan's connections between an ethic of care and gender, argue that Gilligan never claimed definitively that her "different voice" is gendered. It may be the case that Gilligan's findings are ideological, reflecting cultural expectations for women. Some suggest that Gilligan merely articulates and defends the virtues we associate with women (Greeno and Macoby, 1986). Others suggest that while Gilligan proves no empirical correlation between an ethic of care and gender, there is a strong symbolic and cultural correlation between the two. Mansbridge writes that "while statistically there might be only a small difference between males and females in adherence to an ethic of care, culturally an ethic of care is female (Clement, 1996, p. 51). Okin (1990) argues that Gilligan herself is not clear about the correlation between an ethic of care and gender:

> "A problem arises from the fact that it is not clear to what extent Gilligan is asserting generalizations about men's and women's moral thinking. Throughout most of the book, the language implies that strong general statements are being made about "men" and "women." By comparison, in the introduction, Gilligan minimizes her intent to generalize about gender differences in moral thinking" (p. 156).

In any event, the supposed correlation that Gilligan made between gender and an ethic of care no longer seems to hold true. Using the last revisions of Kohlberg's scales, Lawrence Walker found that gender differences had disappeared (1984). Subsequent research has supported this finding.[11] Other studies have found that while differences exist in subjects' use of an ethic of care versus an ethic of justice, these findings are not related to gender but to other demographic variables such as class (Cortese, 1990) or ethnicity (Cannon, 1988; Collins, 1991). Carol Stack (1990), using her "Clyde dilemma" and Gilligan's scoring protocol, found that the African Americans with whom she worked were likely to use both care and justice assertions in determining whether Clyde should assist his ill parents. Gender was not significant in these deliberations.[12]

Joan Tronto (1994) addresses perhaps one of the most serious limitations of Gilligan's work for feminists. Because Gilligan understands an ethic of care almost entirely in terms of personal relationships, she, like Kohlberg, misses critical opportunities to extend the influence of care to the public sphere. In doing so,

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[11] See, for instance, Pratt, Golding, Hunter, and Samson (1988); Smetana, Killan, and Turiel (1991); Walker and Taylor (1991).

[12] The Clyde dilemma is as follows: "Clyde is very torn over a decision he must make. His two sisters are putting pressure on him to leave Washington, DC and go back home to take care of his parents. His mother is bed-ridden and his father recently lost a leg from sugar. One of his sisters has a family and a good job up north, and the other just moved there recently to get married. Clyde's sisters see him as more able to pick up and go back home since he is unmarried and works part-time - - although he keeps trying to get a better job. What should Clyde do?" (1990, p. 22).

Gilligan and Kohlberg "basically leave intact the boundary between public and private life, and between justice and caring."[13] These spheres are not "separate but equal"; instead the public sphere is perceived of as being considerably more important than the private. Since political life is connected with the public sphere, caring becomes outside of and beneath political concern. Tronto concludes: "Hence, the radical potential of Gilligan's ideas have been contained with current boundaries" (p. 96). And while the debate between care and justice is not one about gender according to Tronto- -in fact she argues insistently and persuasively against the essentialism some perceive Gilligan's work to assume- -Tronto does assert that Gilligan's ideas do nothing to transform "the place in our society of women and others who care" (p. 96).

Philosophical Antecedents: Sentiment and Reason

Although the starting point for this project is to consider extensions of an ethic of care into the public sphere, as Tronto encourages, it is important to ground the care – justice debate in its philosophical and historical antecedents. In terms of philosophical antecedents, the care-justice debate is grounded in a long tradition of moral theory, specifically traditions of Sentiment and traditions of Reason. In terms of historical antecedents, Gilligan's work and the attention it brings to gendered understandings of moral reasoning is similarly not a recent development. It too has a

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[13] The boundary between public and private life is one of three moral boundaries Tronto challenges. The other two boundaries are the boundary between "moral and political life," and the "moral point of view" boundary that requires that moral judgments be made from a distant and disinterested posture in contrast to a posture grounded in concrete circumstances (1994).

rich and complex history, and more particularly, these tensions are reflected in the beginnings of the social work profession.

An ethic of care and sentiment: Many writers trace the thinking of various components of an ethic of care to Aristotelian and Humean ethical paradigms of virtue ethics, which focus on the goodness of people's character in contrast to the rightness of their actions (Code, 1991; Sevenhuijsen 1998; Tong, 1993; Tronto, 1994).[14] For Aristotle, moral deliberation that will determine the right thing to do at the right time in the right place to the right person in the right way is always grounded in a particular social and historical context, and requires moral character. Such judgments do not spring from an abstract concept of the good.

Relatedly, Hume, argues that ethical life is guided by moral sentiments. Reason alone cannot move human beings to act morally; emotion and personal concern, cultivated within social and political human relationships, are required.[15] In contrast to Kant, Hume argues that morality is not obedience to some universal law but cultivation of character traits, particularly sympathy, that give one "inward peace of mind, consciousness of integrity" and make one good company to others (Hume, 1975, p. 283). Whereas Kant appeals to universal moral rules arrived at through reason, Hume saw such rules as varying from community to community and changeable by human action inspired by our capacity for sympathy and concern for others. The virtues he affirmed were not military nor puritan virtues, but virtues

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[14] This discussion is admittedly cursory and does not capture the richness of these traditions. No attempts are made to critique the strengths and shortcomings of these perspectives; rather the intent is locate them philosophically within the sentiment tradition.

exhibited in social contexts involving particular relationships. A virtuous person is "a safe companion, an easy friend, a gentle master, an agreeable husband, an indulgent father" (Hume, 1978, p. 606) - - virtues traditionally expected from mothers and wives. Also, in contrast to Kant, Hume gives no central attention to freely chosen relationships between autonomous equals; rather unchosen relationships between intimate unequals (parents and children) are at the center of his moral theory. The main problem Hume's moral theory attempts to solve is intrapersonal and interpersonal conflict over time, not freedom, as in Kant's theory. Groenhout (1998) suggests that an ethic of care, rather than being a variant of virtue ethics, resembles virtue ethics in that both attempt to develop a theory of the good, in contrast to deontological theories that begin from an account of right action. Care theory, however, begins with a personal relationship and the practices that constitute the relationship. This contrasts with virtue ethics' emphasis upon developing a specific conception of human nature and an account of what constitutes a good human life.[16]

Some proponents of care link an ethic of care to communitarian conceptions of justice.[17] Reacting to liberal frameworks of society (such as those of Mill, Rawls,

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[15] For a more extensive analysis of Hume's moral theory and its congruence with virtue ethics and Gilligan's work, see Baier (1987).

[16] There are also interesting connections between Care theory and Agapic ethics developed in a Judeo-Christian tradition. Both are relational ethics emphasizing care to particular others. The motif of care and compassion is central to both in terms of what it means to be moral, and both emphasize responsibilities to live for the other rather than emphasizing or starting with responsibilities to the self (Groenhout, 2001). This discussion, however, is beyond the intent of this chapter.

[17] Distinctions are made within communitarianism between miltitant and moderate communitarians. The former thinkers, characterized by MacIntrye (1988), Taylor (1989), and Sandel (1982) firmly support community control and reject liberal theories. The latter thinkers such as Walzer (1983) emphasize the importance of

and Nozick) that ground human relationships in rights and contracts, communitarian perspectives "take a conception of the right to be based on a conception of the good" and this common good is "constituted by the practices of communities" (Sterba, 1995, p. 82). Thus, communitarians reject attempts to establish a single theory of justice by which to judge every society. Rather principles of justice are regarded as pluralistic and particularistic, derived from differing conceptions of the good that emerge from diverse moral communities. What is due to individuals as a matter of justice depends upon community-derived standards grounded in tradition (MacIntrye, 1988) or current shared understandings of each culture (Walzer, 1983).[18] Avoiding the language of justice and adopting the language of solidarity, communitarians base morality on the shared values, social goals, traditional practices, and cooperative virtues of the group. This stands in contrast, argue communitarians, to the central tenets of liberalism that trump individual autonomy and community neutrality toward conflicting values. Sandel (1982) describes the positive aspect of communal life that is allegedly missed by liberal theory:

> In so far as our constitutive self-understandings comprehend a wider subject than the individual alone, whether a family or tribe or city or class or nation or people, to this extent they define a community in a constitutive sense. And what marks such a community is not merely a spirit of benevolence, or the prevalence of communitarian values, or even certain 'shared final ends' alone,

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various forms of community, including the family and the political state, while attempting to accommodate rather than reject strands in liberal theories.

[18] In this sense Walzer can be called a communitarian. His second criteria for justice, however - the "separate spheres" criterion – is congruent with egalitarian conceptions of justice that commit themselves to alleviate inequality and dominance.

> but a common vocabulary of discourse and a background of implicit practices and understandings (p. 172).

Given communitarian priorities to avoid abstraction, impartiality, and universality, and affirm understandings of the self in relation to context and community, it is not difficult to understand why some proponents of an ethic of care draw from such perspectives in articulating or defending an ethic of care. This affinity to communitariansim, however, is not shared by all who espouse an ethic of care. Tronto (1994), for instance, finds the diminution of rights by communitarians extremely troubling, for without strong conceptions of rights care-givers and communities are apt to see the world only from their perspective, make judgments accordingly, thereby stifling diversity and otherness. As well, traditions and shared meanings of justice are more often based on some points of view than on others, and these groups of power are able to shape and defend their traditions and understandings against the views of those without power (such as those who are economically poor, uneducated or poorly educated, members of ethnic minority groups, and so forth).

An ethic of justice and reason: An ethic of justice, like an ethic of care, is grounded in a long and rich tradition of moral theory. What Gilligan calls "the justice perspective," because of its emphasis upon formal reasoning and rights, is best represented by the tradition of liberal individualism that emerged during the Enlightenment, and more specifically, is best captured in the thinking and writing of

John Locke, Immanuel Kant, and, more recently, John Rawls.[19] In each of their theories, a social contract model becomes the method by which commitments to liberty are achieved. The ideal of autonomy that distinguishes the justice tradition stems from the methodological commitment to the social contract and the substantive commitment to liberty. Moral autonomy is achieved when individuals use reason to discern the content and application of the social contract. Personal autonomy allows individuals to pursue their vision of the good life - - liberty - - in their own way. Rawls' work, paradigmatic of this tradition, is discussed shortly.

Utilitarianians such as Mill and libertarians such as Nozick are also part of the liberal individualism tradition. Along with Locke, Kant, and Rawls they share a commitment to reason as the means by which one finds ethical truth that is objective and universal. They also identify the individual as the focal point of moral concern. This prioritizing of rationalism and individualism is a prime target of criticism by proponents of an ethic of care. There are, of course, many differences between utilitarians, libertarians, and social contract theorists in terms of how they define justice and in their conceptions of ethical norms. Because some of these distinctions

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[19] It is beyond the scope of this project to analyze the factors which shaped the emergence of liberal individualism during the Enlightenment. Tronto (1994) contrasts the tradition of liberal individualism, what she calls universalistic morality, to contextual morality or the tradition of moral sentiments, which can be traced back to Aristotle. She argues that universalistic morality, most closely aligned with Kant, emerges out of social, intellectual, and economic changes in the late eighteenth century (not out of any association between women's morality and moral sentiments). As life changed, moral life based on moral sentiments became more implausible, thus resulting in changing moral theory. The moral minimalism of universalistic ethics was attractive because it more easily accommodated and regulated social conflict in situations characterized by social distance where people no longer knew each other well. See in particular Tronto's Chapter Two, *Universalistic morality and moral sentiments*, for a detailed analysis of these ideas.

become important in understanding the relationship between an ethic of justice and an ethic of care, these three philosophical traditions' conceptions of justice are briefly summarized.[20]

Jeremy Bentham and John Stuart Mill are recognized as developing the first detailed and systematic account of utilitarianism. The heart of utilitarianism, grounded in Bentham and Mill's work, is captured by Mill in the following way:

"Utility" or the "greatest happiness principle" holds that actions are right in proportion as they tend to promote happiness; wrong as they tend to produce the reverse of happiness. By happiness is intended pleasure and the absence of pain . . . (1957, p. 10).

The promotion of human happiness provides a criterion here of right action. As such, whether understood as pleasure or preference satisfaction,[21] happiness can be empirically measured and thus it can serve as an objective measure for judging whether an action is right or wrong. The right action, on balance, is one that promotes the greatest overall net happiness, or positive utility, for the greatest number of people. As such it is a teleological theory, focused on consequences and end purposes; in fact, the results of actions are the only relevant feature in assessing

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[20] Again, this discussion is cursory and does not do justice to the richness of these traditions. No attempts are made to critique the strengths and shortcomings of these perspectives; rather the intent is locate them historically in the "justice tradition" to which Gilligan and Kohlberg refer, and to highlight key ideas problematic to care theorists.

[21] Bentham defined happiness in terms of pleasure and the absence of pain; Mill recognized difference kinds of pleasure and pain and argued that the pleasures of the intellect are intrinsically superior. Hence, a distinction arose within utilitarianism regarding definitions of happiness, with Bentham supporters identified as hedonistic utilitarians and Mill supporters identified as ideal utilitarians (Bentham, 1970; Mill, 1957).

actions. The intentions, feelings, or convictions of the actor are morally irrelevant. Within utilitarianism, distinctions are made between act and rule utilitarianism. Act utilitarians determine the moral rightness of an action by calculating its overall consequences in a particular situation while rule utilitarians consider the consequences of the general observance of a practice.[22]

Justice, for Mill, "is a name for certain classes of moral rules which concern the essentials of human well-being more nearly, and are therefore of more absolute obligation, than any other rules for the guidance of life; and the notion which we have found to be of the essence of justice – that of a right residing in an individual – implies and testifies to this more binding obligation" (1957, p. 73). These rules, however, are subject to an impartial utilitarian calculus; they can be overridden when the greater good demands such action. As such, the principle of utility is a maximizing principle; justice depends on and does not contradict utility. Subsequently, all rules of justice bow to the demands of utility and whatever does the greatest overall good will be just. Mill, unlike many others of the nineteenth century, was willing to extend this equality to women and slaves. At the same time, because of his emphasis upon maximizing the greatest good and in spite of his attention to individual rights, utilitarianism appears not to honor individuals and has implications that are counterintuitive to the respect many persons hold for other persons.[23]

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[22] The distinction between act and rule utilitarianism has become an arena for much debate and discussion (see, for instance, Mill and Bentham's own discussion of these ideas).

[23] For instance, if the lives of five persons in need of organ transplants could be spared by killing one healthy adult person and distributing her organs to the five persons in need, most people would find this unacceptable.

For Rawls as a social contractarian, justice is conceptualized as "justice as fairness" (1971). This notion of justice, as noted earlier, is grounded in the social contract theories of Locke and Rousseau and the deontology of Kant that asserted every person is deserving of respect and to be taken as a moral equal.

The method Rawls proposes to establish principles of justice is a hypothetical social contract, one in which people in an "original position" from behind "a veil of ignorance" together decide as purely rational agents upon principles of justice that will be the result of fair choice. The parties doing the choosing lack certain kinds of knowledge that might make the bargaining process unfair (although no limits are placed on the general knowledge available to them). They do not know what position they hold in society, their own particular life plans, or the society or generation to which they belong. What they do know is that they want to gain as many of life's primary goods as possible. Rawls puts it this way: "No one knows his place in society, his class position or social status, nor does anyone know his fortune in the distribution of natural assets and abilities, his intelligence, strength, and the like. [Nor do the parties know] their conception of the good or their special psychological propensities" (1971, p. 12).

Rawls argues that two principles of justice will emerge from this original position. First, the parties will be concerned to secure their equal liberty: "Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all" (1971, p. 302). Rawls argues that the liberty principle takes precedence over his second principle, the principle of equality. The first part of the equality principle argues that whatever inequalities exist must be acceptable to everyone. Called the "difference principle" or the "maximin principle," this principle permits some inequalities in distribution, but only those that protect or improve the position of the least advantaged in society. It is permissible to maximize the minimum to secure justice. The second part of the equality principle is the principle of equality of opportunity that asserts that each person is to have equal opportunity in achieving the various offices and roles in society. Rawls states it this way:

> Social and economic inequalities are to be arranged so that they are both:
>
> a. To the greatest benefit of the least advantaged, consistent with the just savings principle, and
> b. Attached to offices and positions open to all under conditions of fair equality of opportunity (p. 302).

These two principles, then, form the basic core of Rawls' theory of justice. In contrast to the utilitarian concept of "greatest good," principles of justice are not derived through assessing the utility of actions but by rational choice in a fair setting. These principles are oriented toward the basic structures of society, not toward each act or situation where justice is concerned. Rawls requires that each person benefit from any social inequalities, thereby protecting those who are most disadvantaged from the demands of the greater good of others.

Justice, for libertarians, is the unfettered operation of fair procedures. Robert Nozick's *Anarchy, State, and Utopia* (1974) is paradigmatic of libertarian concerns for a minimal state. This minimal state is based on a minimal set of fundamental Kantian rights: rights against injury by others, rights to freedom of choice and action, and rights to own property. The rights which Nozick affirms are primarily negative rights of non-interference and the right to be left alone. A just society protects rights of property and liberty; social intervention undercuts justice by placing unwarranted demands on individual liberty. Tax laws, for instance, which tax the wealthy at progressively higher rates than those who are less wealthy, and then use these monies to support the poor through welfare payments, are condemned as coercive and unfair because they "appropriate" or "seize" another's labor (1974, p. 172). To seize another's labor is to use that other as a means, not respecting the other as an end in himself/herself. Nozick states:

> Our main conclusions about the state are that a minimal state, limited to the narrow functions of protection against force, theft, fraud, enforcement of contracts, and so on, is justified; that any more extensive state will violate persons' rights not to be forced to do certain things, and is unjustified; and that the minimal state is inspiring as well as right. Two noteworthy implications are that the state may not use its coercive apparatus for the purpose of getting some citizens to aid others, or in order to prohibit activities to people for their own good or protection (p. ix).

Justice for Nozick is limited to the commutative sphere of individual exchange, "from each as they choose; to each as they are chosen" (1974, p. 160). Justice makes no substantive claims, that is, one cannot argue that justice requires any particular distribution of goods. It does not consist of promoting the greatest good nor or protecting the least advantaged. Rather, justice consists only in procedural requirements for fairness in exchange. Whatever distribution of goods results from free choice and exchange is just so long as the beginning point and the exchange itself are fair. It may be unfortunate, for instance, that some individuals are economically poor or lacking good health, but it is not necessarily unfair, provided that free choice in exchange has not been violated.

Obviously Nozick's libertarian views are fundamentally opposed to utilitarianism. Actions which violate another's rights cannot ever be fair, even if it does achieve the greatest net happiness. Nozick is equally opposed to Rawls' contractarianism. The goods which Rawls seeks to distribute fairly are not open for distribution in Nozick's thinking; such goods already belong to people who have invested their labor in them, been given them, or exchanged something else for them. To take such goods away violates individuals' rights and consequently is deeply unfair.

In summary, while these theories of justice have critical distinctions, all stress equality and impartiality. They rest on assumptions of the primacy of the individual, and share the idea that individual self, with liberty, rights, duties, and the capacity to give voluntary consent, exists prior to the social contract. As such, these distinctions stand in sharp contrast to an ethic of care.

Historical Antecedents: Women's Morality and the Profession of Social Work

Thus far, two philosophical traditions - - sentiment and reason - - out of which the ethics of care and justice, respectively, emerge have been considered. It is, of course, not possible to separate these moral traditions from lived historical experiences; both shape and are shaped by the other. For purposes of clarity, however, particular historical events are examined now. These highlight another theme in Gilligan's work, that of gender and morality, the implications of which, as noted earlier, are embraced by feminine thinkers and severely criticized by feminist thinkers. The entire scope of this history is not assessed, but rather that history as it shapes and influences the development of the social work profession. This discussion is limited to certain periods of the nineteenth and early twentieth centuries. Discussion of these ideas is more descriptive than analytic; the goal is to show that Gilligan's work, and the tensions inherent in it with respect to gender and morality, did not occur in a vacuum but were influenced by a lengthy and fertile historical tradition.

Women's Morality: Thinking about "women's morality" is not a late twentieth century invention prompted by Gilligan's research and the critiques of it. Questions such as "Is virtue the same or different in men and women?," "Does society encourage women to develop empowering or disempowering feminine traits?," or "What makes a feminine trait empowering or disempowering?" were pursued by a number of eighteenth and nineteenth century thinkers. The specific content of "women's morality," however, is ambiguous to modern-day readers. The nineteenth century writers who addressed women's issues frequently referred to the "Cult of True Womanhood," using this "phrase as frequently as writers on religion mentioned God. Neither group felt it necessary to define their favorite terms; they simply assumed . . . that readers would intuitively understand exactly what they meant" (Welter, 1966, p. 151). Values of care and nurturance, of religious piety and purity, and of submissiveness and domesticity were emphasized as part of True Womanhood. The moral superiority of women was often suggested, arising in part because of their being female, being a [potential] mother, because they remained untainted by the competitive workings of the marketplace, or as decreed by God. In spite of this strong social and cultural ethos of True Womanhood, however, nineteenth century movements for social reform and suffrage eventually gave voice to different responses from women than those they were trained to believe, responses leading to significant social and political involvements outside of the home. Welter suggests that the cult of True Womanhood, in fact, "carried within in itself the seeds of its own destruction. For if woman was so very little less than the angels, she should surely take a more active part in running the world, especially since men were making such a hash of things" (Welter, 1966, p. 174).

Women's morality in philosophy: As exemplars of these kinds of tensions, Tong (1993) points to several thinkers who offer diverse perspectives on women's morality. The eighteenth-century philosopher Jean Jacques Rousseau, in his classic treatise on education entitled *Emile* (1979), argues that if society heightens the natural differences between rational men and emotional women, men and women will more likely to need each other, and, consequently, more likely to stay together. Education that heightens the rationality of men would include training in virtues such as justice, fortitude, and temperance and would develop men into self-sufficient and moral citizens, husbands, and fathers. Education that heightens the emotional nature of women would include training in nonmoral virtues such as patience, submissiveness, and flexibility and would develop women into emotionally sensitive and responsive wives and mothers. Although Rousseau believes that women could develop masculine virtues, they should not because this might disrupt the harmony of their relationships with men. Rousseau further contends that heightening the differences between men and women will reinforce the boundaries not only between the genders but also between the public and private spheres.

Mary Wollenstonecraft's reactions to Rousseau's ideas are captured in her 1792 monograph, *A Vindication of the Rights of Women*. Calling Rousseau's ideas "nonsense" (p. 108), Wollenstonecraft denies that women are *by nature* more emotional and pleasure-seeking than men. While she does not deny such differences between men and women, Wollenstonecraft attributes such differences not to nature but to the "cages" in which women are locked (p. 105). If women might be allowed the same sort of education as Rousseau's Emile, one which develops the capacity to reason rather than merely be taught "decorum" (p. 106), women will quickly become more moral. Tong (1993) suggests that it is questionable whether Wollenstonecraft truly believes that the best way for women to become more moral is to acquire traditionally ascribed masculine traits, such as rationality. Rather, says Tong, Wollenstonecraft "may simply have believed that it is the most prudent way for them to develop personally and morally within a patriarchal society that prefers male values to female values" (p. 34).

During the nineteenth century, John Stuart Mill, agreeing with Wollenstonecraft, argued that virtue is gender neutral and that any attempts to set up a gender-based double-standard to assess morality is wrong. Furthermore, differences that one perceives in women's morality is the result of a successful patriarchal society's systematic social conditioning. In *On the subjection of women* (1911), Mill wrote:

> "All women are brought up from the very earliest years in the belief that their ideal of character is the very opposite to that of men; not self-will and government by self-control, but submission and yielding to the control of others. All the moralities tell them that it is the duty of women, and all the current sentimentalities that it is their nature, to live for others, to make complete abnegation of themselves, and to have no life but in their affections" (p. 32).

According to Mill, education and political rights, which would break down barriers between private and public life and prevent women from selfish preoccupation with their family's well-being, will prepare women to think as genuine moral agents. Agreeing with Mill that sexual inequality thwarts the development of moral virtue, Harriet Taylor Mill disagreed that education and political rights were sufficient to further women's moral development. Economic security, such that women were not "beholden" to men for their existence, was also necessary (Taylor, 1970).

Denying that virtue is the same for men and women, nineteenth-century thinker Catherine Beecher argued that men and women have separate virtues to develop, and the virtues important to women were those traditionally feminine virtues of nurturance, kindness, empathy, and self-sacrifice, for instance. Separate educations for men and women that would prepare them for their work in separate spheres was essential. To women belonged the sphere of family labor, and to aid women in this work, which Beecher recognized as more fundamental then men's work, she coined the term "domestic science" (Beecher and Stowe, 1873, 1971).

Through the development of families and homes, not only would women create environments conducive to meeting the needs of men, they would create Christlike societies characterized by self-denying benevolence. In their morally powerful roles within the home, women, through their submissive and self-sacrificial examples, would teach virtue to their families.

The ideology of gendered separate spheres as captured in the language of True Womanhood - - private life and its assignment to women, public life and its assignment to men - - emerged during the Industrial Revolution and is connected with capitalism (Hooyman and Gonyea, 1995). Prior to this, men, women, and children all contributed to and participated in the family economy. With the emergence of capitalism, a sharp distinction was created between the private world of women's domestic labor within the household and their new role as biological and social reproducers, and the public world of men, located in the waged labor market, and their roles as producers. Profit as the sole operating principle of the marketplace was widely accepted, and "exonerated the public sphere from obligations of community responsibility. Care-giver values were removed from the mainstream of public life and sequestered in the home as an antidote to the public sphere rather than as a central force in shaping it" (Hooyman and Gonyea, 1995, p. 29). Although the ideology of True Womanhood elevated caring as an important function of family life, such activities remained private, nonmonetized, and nontechnological. As such, they became invisible and devalued in a society that increasingly valued paid labor (Dalley, 1988). Even when care-giving functions were extended beyond the family, as we shall see shortly, such activities were assigned to women who performed them as unpaid or low-waged workers.

Women's morality in organized religion: Organized religion throughout the nineteenth century powerfully reinforced ideas of True Womanhood and private, domestic activities as appropriate spheres of life for women. Women's moral superiority and their moral duties to their husbands and children within the home were supported by influential sermons focused on "women's sphere," rhetoric that served to emphasize women's importance but also contain it. This point is captured by the Reverend Joseph Buckminster's sermon to a group of Boston women in 1810:

> We look to you, ladies, to raise the standard of character in our own sex; we look to you, to guard and fortify those barriers, which still exist in society, against the encroachment of impudence and licentiousness. We look to you for the continuance of domestick purity, for the revival of domestick religion, for the increase of our charities, and the support of what remains of religion in our private habits and publick institutions (Cott, 1977, p. 148).

Thus, within their homes, women were expected to create cheerful and comforting kinds of environments that would draw men and sons to home rather than to saloons. Women whose husbands went elsewhere in search of comfort were criticized harshly for their lack of domestic skills. In these domestic duties, women were encouraged to be accepting of their roles: "Even if we cannot reform the world in a moment, we can begin the work by reforming ourselves and our households - - It is woman's mission. Let her not look away from her own little family circle for the means of producing moral and social reforms, but begin at home" (T.S. Arthur, as quoted in Welter, 1966, p. 163). Should a woman choose to focus her energies outside of the home, the consequences were eternally severe, warned The Rev. Mr. Stearns: "Yours is to determine whether the beautiful order of society . . . shall continue as it has been . . ." or whether "society shall break up and become a chaos of disjointed and unsightly elements" . . . . where women lose not only their happiness but also "that almost magical power, which, in her sphere, she now yields over the destinies of the world" (Welter, p. 173).

As organized religion attempted to contain women within the home, however, it also provided a way for women to move outside of the home and expand the roles traditionally allotted them, although such role extensions continued to be limited and defined by the church (Cott, 1977). The numerous women's maternal and moral reform associations in existence prior to 1850 were allied with the church.[24] Unlike participation in other societies or movements, "church work would not make her [woman] less domestic or submissive, less a True Woman," said the Young Ladies Literary and Missionary Report; rather it was here in benevolence work that women might "labor without the apprehension of detracting from the charms of feminine delicacy" (Welter, 1966, p. 153). As Scott observes in relation to middle-class nineteenth century women, benevolence was "a quality that good Christians were expected to exhibit, especially those whom God had favored with health, wealth, and standing in the community" (1991, p. 12). Knight (1997) argues that the seemingly hearty embrace of these women to benevolence work is not surprising given its

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[24] Examples of maternal and moral reform and relief agencies include Tract and Bible Societies, various missions for the poor, orphan asylums, hospitals, homes for young

gendered permeation in their lives via the benevolence of fathers and husbands. Accustomed to being the beneficiaries of benevolence via gender, their middle and upper-class social status also provided them with opportunities for dispensing benevolence to the poor. These women generally did not perceive the tensions and potential conflicts between deciding what is best for the poor based on their privileged status as leisured women, and their experiences of being confined to domestic roles based on the judgments of husbands and fathers.

Women's morality and key movements in the emergence of the social work profession: The expanded roles for women doing benevolence work, building upon their domestic abilities, offered new opportunities for developing independence, competence, and a sense of importance. Women founded various relief agencies, funded and administered them, managed shelters of various kinds, and visited the poor. These societies also provided a means by which women could connect with a network of peers around issues important to their own lives, and slip away from home confinements from time to time.[25] But when women became too successful in their charitable work, men stepped in with their own poor relief agencies, most notably the Association for Improving the Condition of the Poor, "complete with paid agent, officers, and board of managers, all male" (Katz, 1986, p. 65). Women were assigned

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women, and in most cities and towns, some form of a Female Charitable Society or Ladies Benevolent Society to help widows.

[25] Women involved in benevolence work were primarily middle-class leisured women, motivated by a variety of factors toward their charitable work. The motivations for many stemmed from religious imperatives to save souls and redeem behavior. Others were worried about the loss of social order among the masses. Some hoped to inculcate orphaned girls, in particular, with moral discipline and middle-class values of industry, thrift, temperance, and so forth such that they could fulfill servant roles within their homes (Chambers, 1986; Rauch, 1975).

auxiliary roles in this association as well as in other settings, such as orphanages and Sunday Schools, where they had previously held leadership roles. Lesbock concludes that the 1850 male takeover of important volunteer organizations previously directed by women erased "in symbol and in organizational structure, the appearance of autonomous action by women in the public sphere" (as quoted in Katz, 1986, p. 66).

The Charity Organization Society: These tensions and contradictions in women's morality are also apparent in the emergence of the social work profession in the late 1800s and early 1900s.[26] From the myriad charities that emerged in the nineteenth century, particularly in the aftermath of the Civil War and the economic depressions of the late 1800s, the Charity Organization Society movement (COS), initially established in England and transplanted to the United States in 1877, was organized in an attempt to more systematically and scientifically treat the problem of poverty. Reacting to the growing demands for relief upon a poorly organized and highly fragmented system of service delivery, and believing that poverty could be cured through increased moral development, COS leaders, such as Josephine Shaw Lowell and the Revered S. Humphreys Gurteen, proposed a system of coordination of local charities. This systematic, rational, and scientific method would insure that needy recipients were not misusing the system by receiving aid from several sources.

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[26] Not only does the history of the social work profession illustrate some of these tensions and contradictions in women's morality, the profession's history also illustrates tensions between an ethic of care and an ethic of justice. Rhodes (1985) argues that Gilligan's responsibility mode of moral thinking corresponds to nineteenth century religious communities and the professional models of casework that emerged from this, while a rights mode of moral reasoning, based on liberal individualism, emerged within social work in the 1960s, partially as a response to problems raised by employing a responsibility mode of reasoning. Both modes of moral reasoning are reflected in the NASW Code of Ethics, argues Rhodes.

Each applicant's request for assistance would be thoroughly investigated. Volunteer "friendly visitors" would be assigned to visit needy families. These visitors were to be firm but friendly, and assist families not by bringing alms but by correcting character flaws and inspiring the poor to live more moral lives.[27] These sentiments are captured in the 1877 National Conference of Charities and Corrections report on outdoor relief: Charity should not "be so bestowed as to afford the means of vicious indulgence or encourage continuous improvidence;" neither should outdoor relief be continued as this encouraged the notion "that the State is bound to support all who demand assistance" (as cited in Chambers and Hinding, 1968, p. 97). Chambers and Hinding note that these "anachronistic views," as followed through the pages of the movement's journal, *Charities*, continued to persist through two prolonged economic depressions into the early years of the 20th century.

Gurteen, in his *A Handbook of Charity Organization* (1882), provided concrete advice about administrative details and operating procedures for communities wishing to begin their own COS. This publication also reflected the tensions over sex-roles that were prevalent within the COS and society at large regarding women's roles in controlling the delivery of charity. Gurteen hoped that reputable men would perform the volunteer tasks associated with being a friendly visitor, but he realized this would be unlikely given their time demands. Thus, men would be assigned to administrative and policy positions within the COS; the work of council and district committees would be "man's work." The task of visiting the poor

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[27] For useful critiques of the COS movement, see Chambers and Hinding (1968);Katz (1986); Trattner, (1999).

would be assigned to women. This work, after all, "might well satisfy the ambition of any woman's life to have raised but one family from dependence, idleness and beggary, to self-support, honest labor and independence" (1882, p. 186).[28] In fact, this kind of work would be good to foster discipline, self-control, and educate well-to-do women: surely "the whole complexion of the habits of thought of our women would undergo a change; life itself would become a more serious matter; it would be seen that our women have duties which they owe to the community and to the nation no less than men" (p. 186). Katz, commenting on Gurteen's attempt to define and justify a place for women within the COS movement, argues that:

> [b]y defining women as frivolous, Gurteen could disguise the effect of his scheme, which was not to offer women an exciting new opportunity (after all, they had decades of experience with voluntary charity, including visiting the poor) but to sharply limit their sphere of action . . . the new charity organization societies tried to confine women to the infantry in the war against pauperism (186, p. 79).[29]

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[28] Rauch (1975), in her analysis of the Philadelphia Society for Organizing Charitable Relief and Repressing Mendicancy (SOC), points to numerous arguments made for the appropriateness of using women as friendly visitors. Women's innate characteristics and capabilities of sympathy, self-denial, and gentleness were related to their effectiveness as SOC visitors. Their "quickness of insight, which penetrates behind the disguises of both pretense and reserve . . . reads the real situation of a miserable household" and their greater tact, patience, and gentleness than their male counterparts made them "in all ordinary cases, by far the best visitors of the poor" (p. 245).

[29] See Rauch (1975) for an extended discussion about the conflicts between male administrators and female visitors within the Philadelphia Society for Organizing Charitable Relief and Repressing Mendicancy (SOC). Rauch argues that the SOC flourished, on the one hand, because it offered women more substantive roles outside of the home than previous genteel relief efforts; on the other hand, male condescension toward the visitors' work and their unwillingness initially to allow

In spite of (or perhaps because of) coercive undertones, narrow understandings of poverty as connected to individual moral shortcomings, and attempts at careful containment of women as friendly visitors, the COS movement flourished in the United States.[30] By 1900, 138 organizations were operating. As COSs developed in the early 1900s, they did mellow somewhat in their strict interpretation of poverty as moral shortcomings.[31] Some of this mellowing occurred because of increased interaction with the workers and ideas of the Social Settlements. Cumbler (1980) argues that as women moved into administrative positions, attitudes

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them to move into administrative and board positions infuriated the visitors. Eventually women did move into such positions for "negative reasons that included stereotyped perceptions of women's role and of women's characteristics, and the relative cheapness of female labor" (p. 256).

[30] Although Gurteen attempted to prevent women from moving into administrative positions in the COS movement, he was not entirely successful. Josephine Shaw Lowell, for instance, was a founder of the New York COS, and a member of the New York State Board of Charities. Interestingly, when eulogized upon her death in 1905, she was praised for her presumed innate nurturing abilities: she carried authority by "her charm, her sweet dignity, her simplicity" and "dwelt with motherly sympathy . . . upon the sufferings and the miseries of the world" (as cited in Chambers, 1986, p. 9).

[31] Homer Folks, in 1901, injected a new theme into the COS movement, that of working toward raising the standard of living for the poor. Criticisms of Folks' ideas were intense in subsequent issues of *Charities*; one editor inquired, "Is there any stopping place in following out this principle, short of socialism?" (as cited in Chambers and Hinding, 1968, p. 98). In the 1903 National Conference of Charities and Correction, Folks argued that "sickness is *always one* of the leading causes, and is usually *the* leading cause of dependency" (Chambers and Hinding, p. 100). These ideas became an early impetus for later refinement of ideas and principles within the COS movement - - ideas that would allow the COS movement and the Social Settlement movement (discussed later) to begin working collaboratively. As early as 1905 the COS movement and the Social Settlement movement began working their collaborative efforts as evidenced by the merging of their respective journals, *Charities* and *The Commons* into one journal, *Charities and the Commons*, informed by both branches of social service. At the 1910 National Conference of Charities and Corrections, Jane Addams began her address by noting the convergence of the "Charitables" and the "Radicals," both of whom, "as the result of of a growing awareness of distress and of a slowly deepening perception of its causes, are at last uniting into an effective demand for juster social conditions" (p. 68).

towards the poor changed, resulting in policies and actions more focused on reform efforts and less attention directed toward "hunting for the unworthy poor" (p. 105).

In their attempts to be more scientific in their charity, charity organizations established training schools.[32] Concurrent with this move, volunteer service declined, giving rise to paid agents, now trained in the casework dimensions of friendly visiting.[33] Like volunteers before them, these agents were primarily well-educated, white, religious, middle-class women looking for contexts in which to exercise their intellectual and civic commitments. Charity work, because it emphasized traditional feminine characteristics of caring for others, was a good fit.[34] In particular, impersonal and expert-driven casework, consisting of "those processes which develop personality through adjustments consciously effected, individual by individual, between men and their environment" replaced the work of the prior friendly visitor (Richmond, 1922, p. 98). Women were actively recruited for various training programs in casework because of their inherent nurturing and tender qualities and because they were perceived as "the natural lovers of children" (Smith, 1891, p. 240).

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[32] The transition from using volunteers to employing those with training degrees was not unique to the emerging social work profession but paralled similar changes occurring in other professions such as education, medicine, and community service (Karl, 1984).

[33] Mary Richmond, who directed first the Baltimore COS and then the Philadelphia COS, was particularly influential in calling for systematic training of charity workers. In response to her 1897 speech at the National Conference of Charities and Corrections, where she called for such training, the New York COS responded the following summer by founding the New York Summer School of Applied Philanthropy. These series of courses later expanded to become the first school of social work in the United States - - Columbia University School of Social Work.

[34] Charity work was also a good fit with the goals of middle-class society as it did not challenge or change current understandings of poverty as the result of individual moral shortcomings; instead the new caseworker focused on helping the poor adjust to their environments, regardless of how oppressive such environments might be.

Dr. Earnest Southard, for instance, in recruiting students for his psychiatric social work training program at the Boston Psychopathic Hospital, specified women as his target population because women experience "more changes of the emotional sort in one year than men do in five, and yet are more rational than men" (Cohen, 1958, p. 133).[35] From this transition to casework, along with other social reform efforts such as the Social Settlement movement, the profession of social work emerged. Even from this brief discussion of Charity Organization Societies, it is clear that the tensions between defining appropriate roles for women outside of the home is present within the profession as well as certain assumptions about the emotional constitution of women as being instinctually more loving and sympathetic, an assumption that both opened and limited doors to women beyond the confines of their home.

The Social Settlement: Parallel to the inception and development of the COS movement, the Social Settlement movement, also imported from England, was emerging. In contrast to the COS movement, however, social settlements focused on environmental factors in poverty.[36] Horrified and ashamed by the separation between

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[35] These words were spoken by Esther Cook, Smith College alumna, in her recollections of the Boston Psychopathic Hospital.

[36] See Trattner (1999, pp. 163 - 191) for a useful summary of the similarities between COSs and Social Settlements. In short, both relied heavily on volunteers, were concerned about class divisiveness, believed in a scientific approach to studying urban problems, and were concerned about people's material and spiritual conditions. In contrast, social settlements addressed the social and economic conditions attached to poverty while COSs emphasized individualist moral shortcomings attached to poverty. COS workers were concerned about dependency; Settlement workers were concerned with poverty. Settlement workers worked with the strengths of their neighbors, while COS workers focused on the deficiencies of the poor. In contrast to the COS workers' systematic and rational approach to alleviating poverty, settlement workers had no well-defined methods or goals, preferring instead to be opportunistic and pragmatic. Trattner argues that most settlements "exemplified the democratic ideal in principle and in action, while the organized charities were the very opposite -

classes and urban poverty, settlement house workers moved into neighborhoods deeply affected by poverty. Here they realized first-hand the ways in which poor employment conditions, inadequate wages, substandard housing, poor sanitation, inadequate city government, and lack of educational opportunities affected and shaped the lives of the poor, mostly immigrants from southern and eastern Europe. A plethora of programs and services were offered through social settlements to address the needs of local neighborhoods. Settlement workers did not, however, see themselves as "charities" nor did they see the poor as paupers. Rather, the poor were neighbors who "were superior to them [settlement workers] in knowledge of life and the living conditions in the neighborhood, whereas they [settlement workers] were superior in training and understanding of the problems of social democracy" (Chambers and Hinding, 1968). As well, many settlement workers focused their energies on wider social reform issues such as women's suffrage, protective legislation for women and children, municipal reform, and sanitary and housing reform.[37] Although many settlement workers were people of religious faith (mostly

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- the embodiment of inequality in theory and practice" (p. 167). See Trattner also for a revisionist discussion of the settlements in regards to his argument that settlements were progressive and democratic.

[37] While the social settlement movement at large contrasted sharply with the philosophy of the COS movement, the social settlement movement played out at the local level was not always a unified group. A group of Chicago settlement workers met in 1898 to draft a statement of purpose and goals, only to give up several hours later agreeing on nothing more than that the settlement ought to become a Social Center for Civic Cooperation and an impetus for social reform in the city. And while they were deeply concerned for the plight on immigrants, many held on to racist assumptions towards blacks such that these groups formed their own settlements (Davis, 1967; Jackson, 1978; Trattner, 1999). Even Addams, generally a strong advocate for African Americans, did not challenge the Progressive Party's refusal to seat African American delegates at their 1912 convention.

Protestant but also Catholic, Jewish, and other faiths), they were non-sectarian in their work. The agenda of most social settlements was social reconstruction, not personal redemption of the poor. By 1891, there were six settlements in the United States, 100 by 1900, and over 400 by 1910.[38]

While many who worked in social settlements resembled COS workers in being women, white, educated, and middle-class, the roles played by men and women differed. In the social settlements, women took on more visible leadership roles; in fact, two-thirds of the settlement houses were directed by women. Men, who constituted about one-third of the settlement house workers, assumed front-line roles. From Hull House, one of the most famous social settlements, a strong network of women reformers emerged, including Florence Kelly (labor and consumer advocate), Edith Abbott and Sophonisba Breckinridge (social researchers and key leaders in social work education development at the University of Chicago School of Social Service Administration), Frances Perkins (secretary of labor in the New Deal), Julia Lathrop and Grace Abbott (influential women in the Children's Bureau), and Alice Hamilton (physician and social activist). For educated women in particular - - who

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[38] By 1920, the Social Settlement movement was on the decline. Settlements lost popularity in the wake of World War I when many workers and leaders, including Addams, opposed the war and U.S. involvement in it. Public distrust toward settlement workers grew on account of this, particularly during the Red Scare of 1919 – 1920. Also, post-war prosperity invoked individualistic moral understandings of poverty, and previous concern for social justice faded. Within the social work profession, social workers became preoccupied with professionalization, and casework, which embodied technique and specialization inherent in professionalization, became almost synonymous with social work. The settlement workers' lack of priority to method, for instance, and their commitments to social reform and egalitarianism with their neighbors, did not fit well with the profession's new direction. Of the few settlements that did survive, many lost their reform focus, and instead became local centers that served, rather than changed, the neighborhood.

were largely excluded from law, business, the ministry, or medicine, and who may not have been inclined to teaching, nursing, or library work - - working and living in a settlement house offered an unparalleled opportunity to work in the company of other educated women and men to further social justice.[39] According to Addams, this "subjective necessity" for settlement work, that is, providing constructive opportunities to college graduates, particularly women, for their intellectual and creative pursuits, went along with the objectives necessities of social reform.[40] These reformers kept alive the reform tradition of social work that COS caseworkers neglected. As well, settlement workers played a critical role in challenging the traditional boundaries of public and private, and women's roles in each sphere. Settlement workers helped lead the drive for women's suffrage; they were also instrumental in carving out authoritative roles for women in the arena of public policy. Franklin (1986) suggests that Jane Addams, founder and director of Hull

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[39] See Rousmaniere (1970) for an interesting and extended discussion on the structure of the social settlements as both a colony or home for workers as well as a philanthropic organization. Noting the preponderance of Vassar, Smith, and Wellesley women - - whose college education had been markedly different from other women in such settings as female seminaries - - Rousmaniere concludes that these "young women needed an institution and an activity that would, first, satisfy the service norm as well as their sense of mission and that, second, would support their vulnerable status so that they might regain the equilibrium they had been secure in at college. The seminary woman had no such need, for her education had but socialized her into the traditional female role. Likewise, the Bryn Mawr graduate had few of these problems, since her expectations had not been raised by a faith in the ultimate compatibility of true womanhood and sexless intellect" (p. 64). The colony structure of the settlement movement reproduced their college experiences of communal living.

[40] See Addams (1893) for a discussion of the dialectic between subjective necessity and objective value.

House, symbolized more than any other woman in her times the "new woman who took her place in the world of work" (p. 512).[41]

While the social settlement workers and others in society were actively engaged in suffrage and social reform, a closer look at the discussions around these issues is telling in terms of the reformers' understanding of "Traditional Womanhood," or "Women's Morality." Unlike antebellum women, some of whom emphasized the ways in which women and men were alike and some of whom emphasized differences between men and women, many women of the Progressive era used the difference arguments in their suffrage deliberations. Because men and women were different, women's particular abilities and skills were needed in the

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[41] Addams' popularity peaked between 1909 and 1915. In 1909, she was the first woman elected as president of the National Conference of Charities and Corrections (NCCC) and also the first woman to be given an honorary degree by Yale University. She published six books and more than 150 essays during this time. Her work with the Occupational Standards Committee of the NCCC and its recommendations for reform in industry were adopted by the Progressive Party platform in 1912. Addams' nominating speech for Theodore Roosevelt at the 1912 Progressive party campaign was enthusiastically received and given priority attention in the newspapers, propelling her into high national visibility. Ironically her alignment with partisan politics was the first step in her declining popularity and influence in that era. She was soundly criticized for her affiliations with the Progressive party, most stingingly by Edward Devine of the New York COS who argued that "it was the first political duty of social workers to be persistently and aggressively non-partisan, to maintain such relation with men of social goodwill in all parties as well as insure their cooperation in specific measures for the promotion of the common good" (Davis, 1973, p. 193). Addams' popularity and influence declined further with her opposition to World War I, and her later support for the Deb's Socialist ticket. Among social workers in particular she continued to lose popularity with her stand against professionalization of social workers because of the dangers of looking at social work "too steadily from the business point of view, to transfer it into the psychology of the business world" (Addams, 1926). During Addams' decline, Mary Richmond's promotion of social work's professional identity and her emphasis upon scientific competence in social services became ascendant. Addams did receive the Nobel Peace Prize in 1930, but never regained her prewar reputation.

public sector as well as the private. At the Women's Suffrage Convention in 1898, for instance, Anna Garlin Spencer argued that motherhood provided women with distinctive ethical developments, "that of sympathetic personal insight respecting the needs of the weak and helpless, and of quick-witted, flexible adjustment of means to ends in the physical , mental, and moral training of the undeveloped" (Norton, 1989, p. 257). And government, no longer merely "the coarse and clumsy instrument by which military and police forces are directed" but also the "flexible, changing and delicately adjusted instrument of many and varied educative, charitable and supervisory functions. . . " requires for "these wider and more delicate functions a higher order of electorate, ethically as well as intellectually" found in women's "motherly succor and training" (pp. 256 – 257). Not only would government benefit from women's participation in the suffrage, women would also benefit. Charlotte Perkins Stetson (later Gilman) argued that "the suffrage draws the woman out of her purely personal relations and puts her in relations with her kind, and it broadens her intelligence;" she will no longer be an uneducated mother but "a member of the community" and of better worth to her family (Norton, p. 256). In short, seeing men and women as different changed the dynamics of the suffrage discussion. Previous appeals by women to vote had been based on arguments that because men and women are the same, they had a right to vote. The late 19th and early 20th century reformers based their appeals to vote on arguments of difference between men and women, and consequently, their duty to vote and contribute their distinctive abilities to government.

Jane Addams' writings also appear to reflect the attitudes that men and women had separate and diverse roles in life because of their different constitutions, and she draws upon this in defending an expanded role for women beyond the confines of the home as well as in terms of the suffrage. The problems of cities, such as unsanitary living conditions, contaminated food and water, abandoned and neglected children, and unsafe working conditions, require "city housekeeping," Addams argued. Efforts at city housekeeping have failed because women, as the traditional housekeepers, have not been consulted and men have been as indifferent to civic housekeeping as they have been to household details. If women are unable to have an impact upon their cities because they lack voting power, Addams argued, this would not only be detrimental to cities but would in turn, eventually affect women's abilities to run their households effectively and protect their children (Kraditor, 1965).[42]

Addam's acceptance of inherent differences between men and women is evident in other of her writings as well. In a 1910 article in the *Ladies Home Journal*, Addams suggests that:

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[42] In her 1909 Ladies' Home Journal piece, "Why Women Should Vote," Addams argues this position by providing an example of a woman living in a once comfortable neighborhood and fiercely devoted to protecting her children. With the influx of immigrants, neighborhoods became overcrowded and sanitation became a serious health problem. The mother kept her distance from the immigrants, believing that their concerns and struggles were of no concern to her. Her daughters, however, returning home from college at a time when typhoid was rampant in the neighborhood due to inadequate plumbing, became ill with typhoid. One daughter died; the other was ill for nearly two years. The point of the story, according to Addams, is that the death and illness came to this family not because of the mother's inadequacies, but because she alone no longer was able to protect them from the complexities and challenges of city life (Kraditor, 1965).

> [p]ublic-spirited women who wish to use the ballot, as I know them, do not wish to take over men's affairs. They simply want an opportunity to do their own work and to take care of those affairs which naturally and historically belong to women but which are constantly overlooked and slighted by our political institutions (p. 21).

And in an unpublished poem written to a friend, Addams says that during her intense work at Hull House, she "had forgotten Love," and then concludes:

> That is the way with women folks
> When they attempt the things of men
> They grow intense and love the thing
> Which they so tenderly do rear
> And think that nothing lies beyond
> Which claims a passive tear (Lasch, 1965, p. 18).

Addam's feminism has been discussed and critiqued at length. Those critical of Addams find her feminine strategies to promote social change ineffective and counter-productive. Kraditor (1965) asserts that arguments Addams used to defend women's suffrage were arguments of expediency rather than earlier arguments of justice, that is, men and women are equal and had the same inalienable rights to liberty and equality. Other scholars argue that while Addams and other reformers of the early twentieth century wielded national power, they built their arguments on traditional and restrictive notions of women as the "civilizing and moralizing forces in society" (Conway, 1971, p.174). Consequently, they did nothing for transforming Victorian sexual stereotypes or redefining sex roles within the family. LaCerte's lament, "if only Jane Addams had been a feminist," alleges that Addams had been "assertive, independent, dedicated, practical, and rational in every social cause but feminism" because she failed to challenge traditional sex-role definitions (1976, p.

657). Phillips (1974) asserts that Addams's contrasts between women's worlds of motherhood, civic housekeeping, and social reform through a change of heart and men's worlds of competitive individualism and force as a change agent was disastrous for women. Such contrasts did nothing for women's liberation as "[l]iberation in the end required more than an expansion of domestic values into the world. . . . It required an acceptance of self-assertion and ambition, and an acceptance of the grubby material secular world outside" (p. 65).

Others are more charitable of Addams' feminism. Freedman (1979), for instance, is less critical of Addams' redefinition of woman's roles by extension (as opposed to rejection) of traditional women's spheres in city life. Noting the important work of female institutions in general in the late 19th and early 20th century, Freedman points to social settlements, such as Addams' Hull House, as arenas in which those skills most familiar to women became transformed into skills of social reform and political advocacy.[43] While these gender-separate institutions were grounded in earlier conceptions of "True Womanhood" and used arguments that to complete their traditional tasks in the public sector they needed the vote, Freedman argues that these experiences eventually served to foster more radical feminist postures, such as those held by Elizabeth Cady Stanton and Susan B. Anthony, to end political discrimination against women on the basis of equality.

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[43] Freedman (1979) argues that social settlements count as female institutions because over 3/5 of the participants and leaders were women, and because their emphasis was upon service to women and children. Other separate female organizations which Freedman discusses as arising in this era include the women's club movement, the Women's Christian Temperance Union, various women's colleges, the Women's Trade Union League, and the National Consumers League.

Furthermore, the work of Addams and others like her who advocated for various forms of protective legislation for women and children was grounded in a realistic assessment of social problems and the likelihood that these concerns would not be alleviated soon. Economic security in the early 1900s for most women came through marriage to a steady worker being paid a fair wage. When husbands deserted families and women consequently entered the labor market, the choices faced by women were "not personal autonomy but severe exploitation in dead end jobs" (Chambers, 1986, p. 20). Although Addams appeared to have shared prevailing assumptions about differences between men and women and the appropriateness of domestic roles for women with children, Chambers argues that "there would be appear to be something ahistorical and unrealistic in their [later feminists critical of Addams' feminine change strategies] implied expectation that historical actors can dramatically transcend the ideological and material forces of their own era" (p. 20).[44]

In a similar vein, Knight (1997) suggests that Addams, like many women, "grasped feminism in stages" (p. 131). Knight argues that Addams' essay, "A Modern Lear," was her personal working out of her move from powerlessness in patriarchal benevolent relationship as she experienced it with her father,[45] to desiring

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[44] And yet some women of this era appear to transcend these boundaries. Julia Lathrop's more androgynous position stands in stark contrast to Addams' seeming essentialism. Lathrop argued that "the common dust out of which men and women were made enjoyed no spiritual transmutation when it passed through Adam's rib. . . .The power of tenderness and sympathy and adaptation are those that belong to choice individuals, and not to men or women as such" (Costin, 1983, p. viii). In short, what we see reflected in discussions of appropriate women's roles and spheres during the early days of the social work profession mirror in large part wider discussions of that era, and of today as well.

[45] Knight (1997) argues that it is particularly within Addams' discussions with her father over where she would attend college that they disagreed; later Addams would

a type of social justice characterized by the empowerment of those outside of the circles of power. Contrasting Shakespeare's story of King Lear and his daughter Cordellia to the Pullman Strike of 1894 where Pullman workers revolted against cut wages and continued high rents issued to them by the seemingly generous philanthroper, owner, and employer, George Pullman, Addams is critical of the benevolence of Lear and Pullman. Their seemingly good intentions were not motivated by social reform or empowerment of the disenfranchised, but rather egotistic and selfish concerns of being loved unconditionally (in the case of Lear) or capitalist gains (in the case of Pullman). Interestingly, in spite of her strong critique of Lear and Pullman, Addams does not end her essay with praise for Cordelia or the Pullman strikers. Rather she "chides both for their failure to find pity in their hearts for their selfish kings and for failing to include either Lear or Pullman in their vision of their future emancipation" (p. 129), language, says Knight, consistent with Mill's emphasis on justice as grounded in cultivated sympathetic judgments between equals.[46] Using her experiences of gender and benevolence, Addams was able to understand the relationships between class issues and benevolence. This new understanding was a critical turning point in Addams' continued development as a feminist and social reformer.

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connect her experiences of patriarchal benevolence to those of Shakespeare's Cordelia. Addams had wanted to attend Smith College, then a new women's college in the East, but her father had insisted upon Rockford Seminary, a Seminary whose goal was "individual benevolence: to produce daughters whose polish would reflect well on their fathers" (p. 124).

[46] Knight references Mill's *The Subjection of Woman* (1869) with which Addams was familiar.

This chapter does not exhaustively consider the place of an ethic of care within its philosophical and historical context. Beginning with the Kohlberg – Gilligan discussion of the late twentieth century, it examines more specifically the ideas of Kohlberg and Gilligan as modern-day authors of the care-justice debate, and summarizes critiques of both. Next, this chapter considers conceptual locations for ethics of care and justice within a broader frame of moral ethics. Finally, this chapters assesses more closely the theme of gender, its assignment of women's morality to the private sphere, and an extension of this as worked out in the inception of the social work profession through two key movements, the Charity Organization Societies and the Social Settlements. The intent thus far is to provide background discussion to the larger project of extending an ethic of care to the public sphere. This chapter begins to highlight the tensions inherent in thinking of care, traditionally assigned to women and the private sphere, as something that can be extended to the public sector. The next chapter articulates more specifically the traditional distinctions between an ethic of care and an ethic of justice. This in turn lays the foundation for articulating a definition of care and an ethic of care.

Chapter Three
Toward a Public Ethic of Care

The previous chapter looked backward from the Kohlberg - Gilligan debate and considered the philosophical and historical antecedents to the discussion of the ethics of justice and care. This chapter moves forward in time from the Kohlberg – Gilligan debate with the goal of working toward an understanding of a public ethic of care that will be useful for long-term care. To arrive at this point, the traditional ideal-type distinctions between an ethic of care and an ethic of justice are considered, followed by a discussion of the relationship between the two ethics. The point of this discussion is to arrive at an understanding that an ethic of care and an ethic of justice work in tandem, each providing certain social conditions for the other, each serving as a check on the other's moral adequacy, and each making particular contributions in moral deliberations. With this understanding, an ethic of care that moves beyond its gendered confinement in the private sphere can be articulated; this social and political understanding of an ethic of care is subsequently useful for its extension to the public sphere. This chapter concludes with an analytic framework for reflecting on a public ethic of care in long-term care.

Traditional Distinctions between an Ethic of Care and an Ethic of Justice

Thinkers who espouse an ethic of care have been engaged in what has proved to be an ongoing, and sometimes tedious, conversation with liberal and neo-Kantian philosophy. For some care proponents, the goal of this exchange has been to demonstrate the limitations of the justice perspective, and more generally, deontological philosophy. Such challenges by those who adopt a care perspective have led mainstream moral and political philosophers to respond with eloquent defenses of neo-Kantian and liberal philosophies from what they argue are mischaracterizations of central concepts of autonomy, justice, obligation, impartiality, and universality. These responses, in turn, have led some care proponents to rethink their initial assumptions and integrate categories from mainstream philosophical thought.[1] Others have worked hard at articulating the links between care and justice.[2] This next section presents the contrasts between the two ethics as ideal types, mindful of numerous subtle distinctions with each.

Following Tronto (1994) and Sevenhuijsen (1998), three characteristics differentiate Gilligan's ethic of care from Kohlberg's ethic of justice. First, Gilligan's ethic of care revolves around different moral concepts, those of responsibility and care, than Kohlberg's concepts of rights and rules. The central questions for each ethic are markedly different. An ethic of care considers how best to develop and maintain relationships, while an ethic of justice considers the highest normative principles and rights in situations of moral conflict. Second, an ethic of care is grounded in concrete circumstances rather than being abstract, distant, and formal. Third, an ethic of care is best understood as an activity, that of caring practices, rather than as a set of universal abstract principles. Relatedly, Clement (1996) argues that an ethic of justice differs from an ethic of care in terms of ontology, epistemology, and priorities.

Ontologically, an ethic of care assumes a different starting point than an ethic of justice in terms of how we understand human nature and in particular, how we

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[1] See, for instance, Baron, 1991; Hill, 1991.

[2] See, for instance, Held (1993), Okin (1989), and Walker (1992).

understand the self. An ethic of justice is based on assumptions of human separateness. The self is a detached, isolated, atomistic subject with a pre-determined identity. Such a self is independent, self-determining, and responsible only for her freely-chosen autonomous choices. By contrast, an ethic of care is based on assumptions of relatedness and connectedness and posits a relational self in contrast to the atomistic self of an ethic of justice. This relational self is grounded in concrete relationships with people, and it is in these interactions and behaviors of relationships that one acquires a moral identity. The self is not pre-determined or ahistorical but rather formed in and through specific historical and cultural situations. Sevenhuijsen suggests that the self is a "protagonist in a biography which can contain all kinds of ambiguities and unexpected turns" (1998, p. 56). Thus the construction of the self is an ongoing social practice, "something we do and make within human relations and within specific social and political contexts, and the narrative conventions reflected in these" (p. 56).

These differences in conceptions of the self shape how we understand our obligations to others. An ethic of justice assumes we are detached subjects who stand above and outside of empirical reality where we can determine universal moral obligations. Justice emphasizes choice and will in choosing with whom we will enter into contracts. We enter into obligations with those to whom we freely give our consent. Freedom is the starting point. By contrast, an ethic of care is based on assumptions of relatedness and connectedness. Proponents of an ethic of care argue that rather than consent to obligations, we recognize our obligations to others based upon assumptions of human connectedness as the starting point. Thus, "the general challenge of the ethic of justice is to show how one's obligations to others arise without violating one's individual autonomy, while the general challenge of the ethic of care is to show how one can achieve individual freedom without violating one's moral obligations to others" (Clement, 1996, p. 13).

The differences between an ethic of care and an ethic of justice, because they begin with different views about the self, also lead to asking different central questions. In an ethic of care, which begins with a relational self, the crucial moral questions have to do with responsibilities at the individual and community level: "How can I (we) best express my caring responsibility?" "How can I (we) best deal with vulnerability, suffering, and dependency?" In an ethic of justice, where the central task is establishing rules and principles which autonomous and rational people agree to obey, the crucial moral question becomes "What do I owe others?"

An ethic of care and an ethic of justice also differ in terms of epistemology. Working from an ethic of justice, in order to know how to think and act justly in complex moral situations, one must abstract from the particular aspects of a situation to see how it comes under a general rule. Grimshaw suggests that traditional ethicists "think away" or distance themselves from the unique and particular features of people or situations in which moral decisions must be made (1986, p. 204). The standpoint of the "generalized other" is taken because "moral dignity is based on what we have in common, not in what differentiates us" (Benhabib, 1987, p. 163 - 164). Relatedly, reason is privileged as a way of knowing while emotions are suspect, deterrents to sound reason, leading to the valuing of one's own interests over those of the general public. In Kant's ethics, actions motivated by feelings have no moral worth regardless of how right such actions might be; such actions are based on inclination and subject to fluctuation. Morality, according to Kant, is to be based only on steady reason (1956).

In contrast, an ethic of care requires that to know how to think and act justly, one must work from the "standpoint of the concrete other," making moral decisions on the basis of particular and unique features of a given situation, viewing "every individual as an individual with a concrete history, identity, and affective emotional constitution" (Benhabib, 1987, p. 163-4). The ideal moral agent, says Sevenhuijsen (1998), "stands with both feet in the real world" (p. 59) and comes to know about care by placing oneself as a participant within caring practices. Knowing is a social and dialogic process; thus emotions and experiences are centrally important here, affirmed as a legitimate means to knowing how to think and behave morally (Blum, 1980; Code, 1991; Jaggar, 1989; Sevenhuijsen, 1998).

Finally, an ethic of care can be distinguished from an ethic of justice in terms of the priorities of each. An ethic of care prioritizes maintaining relationships and meeting the needs of those to whom one is connected, while an ethic of justice prioritizes some form of equality that recognizes the precept of treating like cases alike.[3] An ethic of justice, as noted earlier, requires that moral judgments be made from a distant and disinterested standpoint. As such, moral judgments do not rise out of the concrete but out of the requirements of reason from the standpoint of disinterested and disengaged moral actors. From this standpoint, universal principles,

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[3] Different conceptions of justice interpret equality differently. Some forms of equality, such as egalitarian conceptions of justice which focus on positive rights, are more compatible with an ethic of care than libertarian conceptions of justice.

rules, and norms that are equally applicable to everyone, and which every rational person should be able to recognize and accept, emerge. The consequence of this "moral point of view" (Tronto, 1994, p. 9) is that morality is a realm beyond feelings and emotion, not shaped by local custom or tradition, but deferring to depersonalized rational thought.[4]

In this depersonalized context, the job of ethics is to formulate higher level, increasingly more abstract principles that can be appealed to in cases of conflicting interests and rights. The requirements of neutrality, rationality, abstraction, and impartiality provide guidance in searching for a normative basis for identifying general interests and prioritizing among human rights. Morally just decisions, made when correct principles are identified and applied to conflicts in accordance with accepted procedures, are prioritized.[5]

In contrast to an ethic of justice, an ethic of care prioritizes developing and maintaining relationships and caring for those to whom one is connected. As such, it is best understood as an activity, that of caring practices, rather than as a set of

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[4] Recall that Tronto (1994) contrasts this universalistic morality to contextual morality which can be traced back to Aristotle. She argues that universalistic morality, most closely aligned with Kant, emerges out of social, intellectual, and economic changes in the late eighteenth century (not out of any association between women's morality and moral sentiments). As life changed, moral life based on moral sentiments became more implausible, thus resulting in changing moral theory. The moral minimalism of universalistic ethics was attractive because it more easily accommodated and regulated social conflict in situations characterized by social distance where people no longer knew each other well. See in particular Tronto's Chapter Two, *Universalistic morality and moral sentiments*, for a detailed analysis of these ideas.

[5] Kant is most closely allied with this sort of moral point of view and it is best expressed in his categorical imperative (1956). Utilitarians also share interest in principles that are abstract and impartial for making moral judgments even though they are more interested in morality as being about "the good" rather than "the right."

universal abstract principles. As Sevenhuijsen (1998) argues: "Thus, the ethics of care does not primarily concern collisions of rights, but is geared rather towards conflicts of responsibilities. This means that the ethics of care is a practice, a particular manner of perceiving and deliberating, rather than a matter of simply finding a series of rules or principles and applying them to clear-cut moral dilemmas" (p. 51). In this context, the stories that people tell about what they need to live well is a beginning point for moral judgments.

Relationship between an Ethic of Care and an Ethic of Justice

While it may be helpful for conceptual clarity to highlight broadly the differences between traditional ideal-type understandings of an ethic of care in contrast to an ethic of justice, such ideal-types tend to pit one ethic against the other. Focusing on ideal-types, for instance, has led to asking particular kinds of questions, such as which ethic is better in moral deliberation.[6] This focus discourages us from addressing more important questions surrounding the two ethics, particularly questions regarding how the two ethics are related to one another (Clement, 1996). Subsequently, two questions about the relationship between an ethic of justice and an ethic of care are posed. First, is one ethic morally more basic or foundational than the other? Second, how similar or different to each other are these ethics?

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[6] These ideal-types also tend to fall in line with and defend traditional boundaries constructed between private and public life. As well, these ideal types tend to support as central, as with an ethic of justice, or reject, as with an ethic of care, the concept of autonomy.

Is one ethic morally more basic than the other? Some argue that an ethic of justice is morally more basic than an ethic of care. An ethic of justice concerns moral minimums and questions of the "right." Formal moral obligations set forth common boundaries and within these boundaries each of us is free to define our conceptions of the good life. An ethic of care, by contrast, is concerned with questions of the good; this goes beyond moral minimums and concerns matters of moral "extras." Those who argue that justice is more basic than care argue that caring cannot be thought of as obligatory as it must be freely chosen; subsequently it is beyond the call of duty and considered supererogatory. While caring relationships are usually considered integral to a good life, the argument goes, these are matters of individual discretion; no one can require us as a matter of justice to care for someone else and no one can criticize another for choosing not to be a care-giver (unless, of course, they have violated the moral minimums set by justice).

Within the family as well, an arena traditionally reserved for an ethic of care, Okin (1989), in particular, convincingly argues that justice is morally foundational.[7] In Chapter Two, *The family: beyond justice?*, Okin specifically challenges two lines of thinking that lead to the conclusion that the need for justice in families is misguided. One such argument, articulated by Michael Sandel (1982), suggests that the family is beyond justice because it is held together by nobler virtues of affection and generosity. The circumstances in which justice is appropriate are situations in

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[7] The thrust of Okin's arguments is to critique modern political theory from a feminist perspective. She does not explicitly engage the care – justice debate here. In responding, however, to the arguments of Sandel and Bloom, she also critiques the moral Sentiment tradition out of which these thinkers write.

which interests differ and goods are scarce, and thus justice is not appropriate to family life, according to Sandel. The second argument Okin challenges is Allen Bloom's (1987) assertion that "nature" and necessity dictate the hierarchial structure within families. Although Bloom acknowledges that such structures are unjust, they are matters of "natural necessity" to shore up male masculinity and compensate for male selfishness (Okin, p. 39).

In response to Sandel, Okin (1989) argues that Sandel confuses justice as being the primary virtue of social institutions for justice as the highest or noblest of virtues. Okin's position is that justice is primary or most essential in families; virtues such as love and affection, while morally important if not morally superior in families, are forms of supererogation. Furthermore, Okin asserts that Sandel's construal of family life where justice is not foundational "depends on a highly idealized view of the *contemporary* family" (p. 31). In fact, says Okin, the "discovery" of violence within families in the 1970s, and the recognition that the "supererogation that is expected in families often occurs at women's expense" leads us to conclude that "[j]ustice is needed as the primary, meaning most fundamental, moral virtue even in social groupings in which aims are common and affection frequently prevails" (p. 29 - 31).

In response to Bloom, Okin (1989) criticizes his arguments as being based on unsubstantiated facts, as relying heavily on "nature" and particularly reproductive biology to defend traditional sex roles, and as being shoddy in defining key terms such as "nature" and "natural" except "that it is whatever preserves the dominance of the white male elite and enables its member, by philosophizing, to come to terms with their own morality" (p. 38). Okin concludes that there is nothing of natural necessity that makes traditional families unjust; there is "surely nothing in our natures that requires men not to be equal participants in the rearing of their children" (p. 39). And even if Bloom was remotely correct that "natural" selfishness prevented men from meeting such responsibilities, Okin asks "since when did we shape public policy around people's faults?" (39).

Uma Narayan (1995) highlights the importance of justice to a morally adequate life and society.[8] Writing about the fatal neglect of female children in India, she points out that " . . . girl children are systematically and seemingly non-deliberately provided substantially less care – nutritional, medical, and so forth – than are boys" (1995, p. 139). While one could argue that the care of these girls is inadequate, the level of care deemed to be adequate is distorted because it is not adequately informed by justice. Narayan writes: "In some families, without more justice, of a sort that changes the cultural meanings and material implications of having daughters, care will fail to be provided, and many female infants will not grow up to become adult bearers of rights" (1995, p. 139).

Others argue that care is morally more basic than justice. Such advocates point out that there is not a bright line between the domains of obligation and the good. The differences between what is obligatory and supererogatory are matters of cultural interpretation. Benhabib (1992) argues that "the line between matters of

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[8] Narayan is not arguing that justice is more basic than care; in fact, she concludes that both ethics provide the "enabling conditions" for assessing the moral adequacy of the other, a point discussed shortly. Nevertheless, her example of inadequate care informed an inadequate notion of justice is a good example of the how justice can be understood as morally more foundational than care.

justice and those of the good life is not given by some moral dictionary, but evolves as a result of historical and cultural struggles" (p. 75). Some have argued, for instance, that the purported neutrality of the liberal state involves some conception of the good. Furthermore, an ethic of care does set absolute moral requirements that are obligatory. All of us, at different points in our lives, will need care if we are to flourish and grow. None of us would be autonomous individuals, if we accept that oneself is socially constructed, without an ethic of care. And while one cannot be obligated to care in the same way that one is obligated to pay taxes or meet our other contractual obligations, one can be expected to be responsible. Tronto (1994) is helpful here in distinguishing obligations from responsibility.[9] Obligations, as defined from a justice perspective, are formal philosophical or political concepts arising out of promises that we have voluntarily made. When asked, "What do we as members of society owe to another person (or group or community), obligations are most often reflected in formal agreements of stated duties. By contrast, the concept of responsibility is more sociological or anthropological, says Tronto. It is a term that "is embeddeded in a set of implicit cultural practices." In attempting to answer the question of what we owe others, the notion of responsibility to care is "more ambiguous" but also more useful in considering what we should do for each other (p. 132).

Others who argue that care is morally more basic than justice assert that minimum levels of care are a precondition for justice. Held (1995) asserts that care is the most general and foundational moral value; justice is an important but more

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[9] Tronto's notion of responsibility is developed further in Chapters Four and Six.

narrow value within a care framework. Care is basic because without care, there would be no life at all. She writes: "There has . . . been little justice within the family, but much care; so we can have care without justice. Without care, however, there would be no persons to respect, either in the public system of rights – even if it could be just - or in the family" (p. 131).

In a similar line of argument, Kroeger-Mapes (1994) also argues that care is a necessary base for an ethic of justice. While an ethic of justice gives the appearance of being a universal, self-supporting moral framework, it is in fact undergirded by the moral labor attached to caring. Solely following an ethic of justice, suggests Kroeger-Mapes, "would result in a place where none of us could thrive, endure, or perhaps even survive. For literally everyone to follow an ethic of rights would amount to the physical, psychological, and emotional neglect of virtually everyone" (p. 115). Prioritizing individual autonomy and respecting rights raises the problem of

> who cares for those who are powerless, who are not recognized as being autonomous, or who are incapable of autonomy . . . and even if we believe that human existence could be sustained over the generations in such a circumstance, itself an arguable claim, we have to ask: Do we want to live in such a place? (p. 115).

To such arguments, Clement (1996) responds that while care might be more necessary than justice for survival, it is a leap then to suggest that care is morally more basic than justice. Our concern is not only for a morally adequate life but extends as well to a morally adequate society. Both care and justice are essential for this.

Nel Noddings (1984) is a strong defender of an ethic of care and of its foundational status as a basic moral concept in contrast to an ethic of justice. In particular, she rejects Kantian universalizability except in the universal accessibility of a caring attitude. Caring, for Noddings, is the basic ethical relation. For her the fundamental question of ethics is how to meet the other morally. Her response is that "one must always meet the other as one-caring. From this there is no escape for one who would be caring" (p. 201). According to Noddings, caring requires real encounters with other individuals. Ethically, we meet others whom we encounter as one-caring. Caring does not include any and all positive concerns one might have for another but rather has three elements. First, caring requires motivational engrossment or displacement in another. It is a receptive mode of consciousness wherein "we receive what is there as nearly as possible without evaluation or assessment" (p. 34). Second, caring requires being present to the other. Third, care requires an action component - care-taking – such as protection or nurture. In short, caring is a "readiness to bestow and spend oneself and make oneself available" (p. 19).

Noddings's difficulty with universalizable principles and her application of caring as a basic guide to ethical relations is captured in her discussion of the case of Ms. Brown, wherein Ms. Brown had promised to attend a concert with her husband but finds that her child is ill. She must decide whether to attend the concert with her husband or stay at home with her child. Noddings describes the difficulty with principles this way:

> Sometimes the decision is easy: The child is obviously too ill to leave or the child is hardly ill at all and happily engaged in some activity. But often the

> dilemma is real, and we struggle with it. There is fever, and, while there is no real danger, the child keeps asking, 'Mother, *must* you go?' The solution to this sort of conflict cannot be codifed. Slogans such as 'Put your husband (child) first!' are quite useless. There are times when he must come first; there are times when he cannot (1984, p. 52).

Noddings's response to this dilemma is telling in terms of her refusal to accept universal principles other than the requirement of caring. Noddings writes:

> When she [Ms. Brown] decides, if she cares, she decides not by formula, nor by a process of strict 'rational decision making.' There is . . . . a turning point. She turns away from the abstract formulation of the problem and looks again at the persons for whom she cares. Perhaps her child is still anxious and irritable; she receives his pain clearly. Perhaps her husband is merely annoyed, not hurt; perhaps, at some deeper level, he too wants only support for his best (i.e. caring) self. If she sees this, having received both persons, she decides to stay with the child . . . [Her decision] is right or wrong according to how faithfully it was rooted in caring - - that is, in a genuine response to the perceived needs of others (1984, p. 53).

Noddings's views about the basic foundational status of an ethic of care generates much criticism. This criticism is directed in two general areas - - Noddings's assertion that justice is not foundational, and her lack of regard for the burdens of carework. Regarding the first, Bubeck (1995), for instance, in response to Ms. Brown's dilemma, argues that at least two principles of justice are indeed present in Ms. Brown's deliberations. Given that some harm will occur from Ms. Brown's decision, Ms. Brown must decide which course of action will result in the least harm; thus the principle of harm minimization is at work. It could also be possible that the principle of equality in care operates in such situations. Imagine, says Bubeck, that the ill child has a sibling also in need of attention. To direct all of one's caring toward the ill child, leaving the healthy child to fend for herself can potentially be unjust for the healthy child. Even if such principles are not used explicitly by a care-giver, Bubeck concludes that "these principles are a necessary part of an ethic of care since a carer will invariably find herself in circumstances of justice and will use such principles to inform her action" (1995, p. 205).

Card's (1990) criticism of Noddings' work is perhaps most succinct in respresenting the criticism that Noddings is inattentive to the burdens of carework for the care-giver. Card writes:

> On the one hand, such an ethic excludes too much. If caring involves real encounters with others, we have excluded as ethically significant our relationships with most people in the world, people whom we will never know personally, and yet whose lives we have affected and continue to affect in far-reaching and often destructive ways. Given that we affect far more people than we can possibly hope to meet, "we need an ethic that applies to our relations with people with whom we are connected only by relations of cause and effect . . . (p. 105).

On the other hand, argues Card, Noddings's ethic of care "also threatens to include too much by valorizing relationships that sheerly exploit carers" (p. 105). Leaving an abusive relationship, an act of "diminished ethical ideal" according to

Noddings (1984, p. 114), is encouraged by Card: "I should have thought the richness of our ethical ideals enabled us to reject bad relationships and freed us up for ethically fuller ones" (p. 106).

Reflecting Card's (1990) theme of valorizing relationships that exploit carers, others critique Noddings's response to women who might feel burdened by their carework. Noddings recognizes that care-givers can be burdened by their work, and thus she encourages them to look after themselves. Noddings, however, understands the dangers of burdened care-givers to be that they will not be able to care joyously. She does not recognize that it might be the case that care-givers feel burdened because they are burdened, and perhaps unjustly burdened. Instead, Noddings suggests that women who feel burdened by their responsibilities perhaps feel they need recognition for their work; strong women, according to Noddings, do not need such recognition for their work. Hence Noddings suggests that burdened women "learn how to maintain themselves as ones-caring through a general strengthening of self-image" (1984, p. 128). To this, Bubeck (1995) responds that "what is potentially an occasion for a critical discussion of women's unjust material benefits and burdens- -the recognition of women feeling overworked and underpaid- -is thus turned into an exercise of blaming the victim" (p. 207 – 208).

The position assumed here in arguing for a public ethic of care is that it is a losing battle to determine which ethic is more basic. Whenever we find a way to say that one ethic is more basic than the other, we can find yet another way to trump this assertion. Both ethics capture something essential about morality. It is the case that certain levels of justice, in which persons are treated as autonomous individuals, presupposes an ethic of care where dependent individuals have been nurtured to autonomy. Relatedly, in states of injustice where one is constantly under attack, it is difficult to imagine that the care required by an ethic of care needed to flourish is forthcoming. Card (1990) reflects:

> Where I disagree is on the need to both supplement and limit care with justice. In one sense caring *is* more basic to human life than justice: we can *survive* without justice more easily than without caring. However, this is part of the human tragedy because, in another sense, justice is also basic: life can be *worth* living despite the absence of caring from most people in the world, but in a densely populated high-tech world, life is not apt to be *worth* living without justice from a great many people, including many whom we will never know (107).

Baier (1995) also comes to this conclusion in her analysis of immigration policy through the lens an ethic of justice and an ethic of care. She concludes that our immigration policies, "like most other social policies, have to be both caring and just, if they are to be morally acceptable" (p. 152). Thus, while it will be humane to give special treatment to applicants with relatives who are residents, and special treatment in emergencies to our bordering neighbors, it would as well be "inhumane and uncaring if the claims of need from non-neighbors were drowned out by closer and so louder demands" (p. 152).

Not only do the two ethics presuppose a foundation for the other ethic's existence, each is foundational for assessing the moral adequacy of the other. Each ethic assists us in determining better or worse versions of the other ethic. For instance, an ethic of care that requires or endorses an action that is clearly unjust can be seen as such through the lens of an ethic of justice. Conversely, an ethic of justice that requires or endorses an action that is clearly uncaring can be seen as such through the lens of an ethic of care. Narayan (1995) captures this tension when she suggests that each ethic provides the "enabling conditions" for the other. While an ethic of care is committed to meeting needs, by itself it cannot provide the conditions that allow us to properly understand the needs of others. Instead, only "serious attention to considerations of justice . . . would enable the powerless to seriously participate in the social and political discourse where such needs are contested and defined" (p. 139). But care is integral as well. Narayan writes:

> Improvements along care dimensions, such as attentiveness to and concern for human needs and human suffering might provide the enabling conditions for more adequate forms of justice. For instance, attention to the needs, predicaments and suffering of the impoverished and destitute in affluent western societies might result in social policies that institutionalize welfare rights, rights to adequate medical care, and so forth (p. 139).

To sum, neither ethic is morally more basic than the other in relationship to each other. Both require certain social conditions provided by the other ethic, and each serves as a check for the moral adequacy of the other.

How similar or different are the two ethics to each other? Turning now to the second question about the relationship between an ethic of care and an ethic of justice, how similar or different the ideal versions of each ethic are to the other is considered. Here, two different responses are characteristic: first, both ethics converge into a single comprehensive ethic; second, the ethics remain distinct, providing alternative understandings to any given situation. Both characteristic responses and critiques of them are summarized next, followed by a discussion of a third way of understanding the relationship between the two ethics. This third view is important to a public ethic of care in long-term care.

Gilligan (1982), in her earliest work, *seems* to conclude that both ethics, at their best, converge into a single comprehensive ethic, although her later writings reflect a shift. In earlier writings, Gilligan argues that in their most developed forms, the ethic of justice and the ethic of care "converge in the realization that just as inequality adversely affects both parties in an unequal relationship, so too violence is destructive for everyone involved" (p. 174). When attempts are made to combine the two ethics into one, the care ethic is typically assimilated into an ethic of justice. Kohlberg, in responding to Gilligan's work, has granted that care is morally important but he does this by treating care as supplementary to universal principles (Kohlberg, Levine, and Hewer, 1984). Others fit care into justice under justice's concern for benevolence.

Critics of this "convergence" response suggest that bringing both ethics together in a single ethical system distorts an ethic of care. Clement (1996), for instance, in response to Gilligan, argues that Gilligan's synthesis represents a minimal sense of convergence - - a convergence in realization or conclusion - - but that the two ethics do not converge into a single ethic. For the latter to occur, the two ethics would have to converge in every way, including priorities, ontology, and methodology. While the distinctions between the two ethics are sometimes distorted, even in their ideal forms, Clement suggests:

> the two ethics draw our attention to different dimensions of any given situation – the ethic of justice to hierarchies among individuals, the ethic of care to the sense of connection among individuals. . . [while] these different dimensions are related to one another in ways that are often overlooked; for instance, an individual can achieve personal autonomy only by being nurtured by others. However, these dimensions remain distinct; neither ethic can be reduced to the other (p. 119).

Fitting care into benevolence also distorts an ethic of care. Benevolence is directed toward people in general while care is directed toward particular individuals. Furthermore, it is also difficult to think of care in terms of traditional obligation theory. Certainly care involves obligations, or responsibilities to others, but such obligations motivated only by a sense of duty distort care also. Finally, assimilating care into justice is not only potentially distorting of an ethic of care but dangerous to its continued existence. Just as the well-intentioned integration of social groups can lead to the destruction of minority cultures, some advocates of an ethic of care fear this same kind of destruction with assimilating care into justice.

The second response is that the two ethics provide independent and alternative orientations to any given situation, just as one, using Gilligan's gestalt switch analogy (1987), can see either a duck or a rabbit in a single scene. According to Gilligan, the figure one sees depends not only upon features of the array but also on past experiences or expectations. Justice and care denote different ways of organizing the basic elements of moral judgment in terms of self, others, and relationships. For those who work from a justice framework, "the self as a moral agent stands as the figure against a ground of social relationships, judging the conflicting claims of self and others against a standard of inequality or equal respect (the Categorical Imperative, the Golden Rule)" (p. 23). Working from a care perspective, "the relationship becomes the figure, defining self and others," the self perceives and responds to needs of others, and the central moral question shifts from "'What is just?" to "How to respond?'" (p. 23). Differences between the two ethics are emphasized here. Ruddick asserts that "the two moral orientations foster distinctive cognitive capacities, appeal to distinctive ideals of rationality, elicit distinctive moral emotions, presume distinctive conceptions of identity and relationships, recognize distinctive virtues and make distinctive requirements on institutions (1995, p. 262). These two irreducibly different perspectives can dialogue with and inform each other, they can serve as checks on each other, but they cannot be brought together to form a comprehensive perspective.

Certainly the gestalt view solves the problem of an ethic of care being distortedly assimilated into an ethic of justice. The gestalt view is not unproblematic, however. There is no necessary connection between a rabbit and a duck orientation as there is between justice and care. Jaggar suggests that "it is no more than a contingent fact that the outline of the duck can also be seen as the shape of a rabbit and vice versa, whereas it is not contingent that particular situations gain their meaning from social structures and that social structures exist only through their instantiation in particular situations" (1995, p. 20). When these ethics are viewed in interaction with each other, we find that the interaction leads to new information or new understandings that would not have been possible had a focus only on one ethic in isolation from the other been maintained. Subsequently, it is reasonable to conclude that the two ethics are interrelated.

While the convergence view tends to hide the distinctiveness of the care ethic, the gestalt view focuses so much on the uniqueness of each ethic that it tends to hide some of the ways in which the ethics can inform and interact with each other. A third account of the relationship between the ethics, then, points to understanding these ethics as distinct ethics that can be integrated in the deliberations of any given situation, public or private. Each ethic will make distinct contributions in moral deliberations. Using an example from Clement (1996), the ethic of justice in the Heinz dilemma is decisive regarding the value of life of Heinz' wife over the value of property. The ethic of care is useful in considering how best to secure the drug, drawing upon relationships rather than stealing it.

In a similar vein, Calhoun (1988) suggests, given that an ethic of justice has had "centuries of workout," we focus intentionally upon what an ethic of care can bring to our moral and political deliberations" (p. 453). She refuses to engage either the convergence or the gestalt view of the relationship between the two ethics. It may well be, for instance, that within an ethic of justice, one can justify partiality towards those to whom one has special moral obligations, such as family or friends.[10] It may also be that within an ethic of justice there is an implicit understanding that we do not

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[10] George Sher, for instance, argues that from a Rawlsian contractarian point of view, it may well be the case the rules will be selected that grant *all* agents the right to be partial toward those to whom they have special obligations (1987).

come to our moral judgments solely through rational, independent reflection, but rely as well on social determinants of moral knowledge. Similarly, such an understanding might exist about the self, autonomy, and the social conditions necessary for achieving autonomy. Calhoun (1988) argues, however, that because an ethic of justice has not focused intentionally upon such themes but rather on rights of non-interference, impartiality, rationality, autonomy, and principles, it has crystallized into a tradition that has nonlogical implications.[11] Even if an ethic of justice "could consistently accommodate the ethics of care, the critical point is that the theorists in the justice tradition have not said much, except in passing, about the ethics of care, and are unlikely to say much in the future without a radical shift in priorities" (p. 453). This silence does not logically imply that the things to which an ethic of care attends are unimportant, but it does have this nonlogical implication.[12] Subsequently, Calhoun calls for a shift in theoretical priorities whereby an ethic of care is brought to center stage.

Integrating both ethics into moral deliberation will not simplify the deliberative process. Bringing an ethic of care more intentionally into the deliberative process may obscure further the range and content of moral discussions. The contributions of the ethics will not always be consistent with each other. There will be tensions between the two ethics that cannot be resolved easily, if at all. But this is not new. Justice principles also often conflict and often there is no

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[11] Calhoun does not take on a particular ethical theory or thinker to task. Rather the cumulative effect of moral theorizing about a restricted range of moral problems leads to nonlogical implications.

metaprinciple that points to a easy reconciliation. What we can be more certain of, however, is that our moral reasoning will be richer and more adequate as it considers all relevant considerations – considerations to which both an ethic of justice and an ethic of care can point us.

This last assertion, however, that our moral reasoning will be richer and more adequate, is a claim that needs to be defended. In turning to this, the debate between the relationship between an ethic of care and an ethic of justice and focus is left behind to focus intentionally upon an ethic of care. The starting point is that an ethic of care, understood as neither more or less foundational than an ethic of justice, can make distinct contributions to the deliberations of any given situation, public or private. In short, an ethic of care has something useful to offer to moral thinking, and in particular, to reconceptualizing social and political discourses and practices. This discussion begins by defining an ethic of care, and in particular, a public ethic of care. In subsequent chapters, as an application of a public ethic of care is considered, the usefulness of an ethic of care in moral and political deliberations becomes clear.

Defining a Public Ethic of Care

Defining care and an ethic of care: Contrary to what may be common understandings of care, "care is not just about changing nappies, cleaning the house and looking after the elderly; it is an activity in which the understanding of needs is central" (Sevenhuijsen, 1998, p. 82). Fisher and Tronto (1990) define care as follows:

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[12] For example, when psychological researchers study only aggression and its role in human motivation, the nonlogical implication of this focus is that aggression is the most important behavioral motivation.

> On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair 'our world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web (p. 40).

Several features of this definition are noteworthy. First, care is a species activity, suggesting that how humans care for each other is one of the features that make people human. It is not restricted to dyadic and intimate relationships, and thus can function in larger social and political contexts as well as in private contexts. Second, care is defined as a disposition and as an activity - - as a practice - - not as a set of principles that must be determined and followed, or as an emotion. As a practice, it involves both thought and action that are interrelated and directed toward some end.[13] Sevenhuijsen (1998) interprets such practices within a social constructivist and hermeneutical framework.[14] Third, the reason we care is to live in

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[13] Tronto rejects Noddings' understanding of care as "essentially nonrational" (Noddings, 1984, p. 25).

[14] To this discussion of care as a social practice, Sevenhuijsen argues for interpreting such practices within a social constructivist and hermeneutical framework rather than in the context of communitarian notions of social practice (to counter functionalism and tendencies toward homogeneity implicit in communitarianism). Within a social constructivist and hermeneutical framework, different sorts of moral vocabularies and moral considerations can be expressed. Sevenhuijsen draws upon Frazer's and Lacey's understanding of social practice as "human action which is socially based and organized, underpinned by formal or informal institutions, usually a combination of these" (1993, p. 17). Care as a social practice understood in this way suggests that participants understand and interpret their needs for care based upon formal and informal rules and traditions, implicit and explicit frameworks, contested rules and norms, and interpretive conventions. Perceptions of needs and the way in which caring acts are perceived and performed varies "'according to the situation and social and institutional contexts, and depends upon a variety of factors, such as norms and

the world as well as possible. Fisher and Tronto (1990) suggest that this provides a flexible standard for determining good care. While the particular meanings of care vary between societies and groups, the need for care is universal. To judge that a given society is morally admirable, "it must, among other things, adequately provide for care of its members and its territory" (Tronto, 1994, p. 126).[15] Fourth, caring as an activity occurs in a variety of public and private settings. It is not restricted to the family, but permeates a variety of social, economic, and political institutions. It takes as its starting point the needs of others.

Fisher and Tronto (1990) further develop their definition of care and their understanding of an ethic of care by exploring four analytically separate but interconnected phases of caring. From these four phases of care arise four ethical elements which further define their conception of an ethic of care. The first phase, "caring about," recognizes that a need for caring exists and that caring is necessary. This phase recognizes that needs and responses to needs are culturally and individually shaped, and thus an accurate assessment of perceived needs must occur. While caring often assumes highly individualized care, it need not. It is possible, says Tronto, to "describe caring about on a social and political level," and consider society's approach to health care, for example, in caring terms (1994, p. 106).

The moral aspect of caring that attaches to the phase of "caring about" is

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rules about good caring and the relational dynamics between the actors concerned" (p. 22).

[15] Tronto (1994) is careful to avoid the conclusion that a society that *only* provided care would be automatically judged moral. There are other important moral precepts; however keeping only these precepts leaves an account of morality incomplete if it ignores the central role of caring in human life.

attentiveness. Attentiveness is required to recognize that there is a need about which to be concerned. Absence of attentiveness, that is, intentionally ignoring others and their needs, constitutes a moral evil. Increasing attentiveness requires that an awareness of care become more prominent in our lives, that care issues currently on the periphery become more central, and that we come to recognize that those different from ourselves, the "others," matter.

In the second phase of caring, "taking care of," someone or some group assumes some responsibility for the need that has been identified and determines how best to respond to it. This phase involves notions of agency and responsibility in the caring process; that is, if one believes that a problem exists about which something can be done, then one begins to think about and respond to needs. Resources of time, money, and skill are needed in "taking care of."

The "taking care of" phase of care makes responsibility into a central moral category. Tronto understands responsibility as imbedded in cultural practices rather than in a formal rules or contractual promises. In this way, she contrasts the notion of responsibility with contemporary political or philosophical notions which emphasize formal obligations to which autonomous individuals freely commit. While responsibility is embedded in cultural practices, Tronto argues that questions about responsibilities can become political in that they become matters for public debate. Rather than a focus upon obligations and the accompanying formal and legal bonds and agreements in political life, responsibility would require addressing questions about the responsibilities we owe to each other and to society. Such questions, Tronto notes, are more ambiguous than obligation but yet we are "better served by focusing on a flexible notion of responsibility than we are by continuing to use obligation as the basis for understanding what people should do for each other" (1994, p. 133).

The third phase of caring, "care-giving," is the concrete meeting of needs by individuals and organizations. Typically this is the physical, "hands-on" work of care, and usually involves direct contact with care-receivers.[16]

The "care-giving" dimension gives rise to the importance of competence as a moral action. To demonstrate that one cares, caring work needs to be performed competently (assuming of course, that resources are in place to do so). Good intentions to "care about" and "take care of" are insufficient unless such work is done competently. Competence as a moral category serves as a check on those who routinely "take care of" situations without actually following through to see if the desired outcomes are achieved. Those who take care of a problem but feel no responsibility to supervise or interact with care-givers and care-receivers to assess whether competent care is delivered enjoy a particular form of privilege: "privileged irresponsibility" (Tronto, 1994, p. 121). Thus, incompetent care is not only a technical problem but a moral problem as well (Tronto, 1998).

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[16] Tronto generally does not include the giving of money as a dimension of this third phase of care-giving. Providing money, she argues is more a form of the 'taking care of' phase in that it provides resources for carework but in and of itself, does not do the work of care-giving. In fact, a great deal of work is needed to translate money into meeting human needs. Tronto insists upon this distinction because she believes, correctly I think, that we in the United States too quickly equate the giving of money with the meeting of needs, thus leading to an undervaluation of people who do carework.

The fourth phase, "care-receiving," involves the response of the individual, group, or thing that has received care. The responses of care-receivers provide a means whereby care-givers can assess whether needs have been accurately identified and met in a way acceptable to both care-givers and care-receivers.

The moral aspect of caring that attaches to the phase of "care-receiving" is responsiveness. Because care is concerned with experiences of vulnerability and inequality, responsiveness "requires that we remain alert to the possibilities for abuse that arise with vulnerability" (1994, p. 135). Tronto notes that responsiveness is not the same as Kohlberg's notion of reciprocity. According to Kohlberg, without reciprocity where one takes the position of the other, moral growth could not occur. Responsiveness, by contrast, recognizes the vulnerability, dependency, and inequality that accompanies a need for care. It does not assume that people are interchangeable such that to understand the needs of others, one simply puts oneself into the situation of the other. Responsiveness requires that we consider the other's position as it is expressed by that person; thus, "one is engaged from the standpoint of the other, but not simply by presuming that the other is exactly like the self" (p. 136).

Good care requires that these four phases and moral elements be integrated into a holistic framework. Good care is not easy to provide. It requires a deep and thoughtful knowledge of the situation and participants. It requires a willingness to make sound judgments about needs, conflicting needs, and strategies for meeting needs, and rests upon judgments that extend far beyond personal awareness to the realm of the social and political. It requires adequate resources. And the provision of good care - - care that takes as its central moral focus the question of how we can best meet our caring responsibilities - - does not remove it from facing serious moral dilemmas. Determining needs and prioritizing which needs to meet, avoiding parochialism while providing individualized and attentive care, and reconciling autonomy and equality with care are substantive ethical issues that must be addressed if an ethic of care is to have moral value. These dilemmas will be considered in more detail in subsequent chapters.

Fisher and Tronto's (1990) understanding of care and an ethic of care is a useful construction for this project because it places care in a full moral and political context and encourages us to develop a socio-political vision of care. As such it responds to and moves beyond many of the earlier criticisms of an ethic of care. Understanding care not only as a disposition but as a practice, involving a wide range of necessary activities in a society in which there can be open and equal discussion, removes it from its confinement in the private sphere, where it is trivialized, sentimentalized, and devalued. Understanding that caring practices are not confined to use by women frees it from its essentialism and the oppressiveness that historically has accompanied this. Understanding care as an integral part of our existence - - that all of us, at some time or another have needed and will likely need the care of others to sustain us - - can further the undoing of our current devaluing of care work and the people who do such work. Only by locating care in a larger context can we hope that such a major part of our life, often treated as a marginal piece of existence, be transformed.

<u>Extending an ethic of care to the public sphere</u>: Tronto and others argue it is both morally important and theoretically possible to transform a private ethic of care

into a public, political ethic of care. An intentional integration of care into public life can help us begin to rethink and broaden several categories. While an ethic of justice has focused upon our similarities as moral selves, and has understood justice as treating like cases similarly, we have had few substantive discussions about human differences. Calhoun (1988) argues that "[u]nless moral theory shifts its priority to knowledgeable discussions of human differences – particularly differences tied to gender, race, class, and power – lists and ranks orderings of basic human interests and rights as well as the political deployment of those lists are likely to be sexist, racist, and classist" (p. 456). Tronto calls this the problem of "otherness," and argues that it has developed from the assumption that "others" are like "us" when in fact they may not be.

A public ethic of care can also help us rethink the notion of moral and personal autonomy, a distinguishing feature of justice traditions. Rather than rejecting an ethic of care because women's autonomy is sacrificed, as some have argued, or valorizing care because it seems to do away with individualistic conceptions of autonomy, as others have argued, the relationship between care and autonomy can be more fully developed. A recognition of the social determinants of autonomy can move us beyond thinking of autonomy narrowly in terms of the psychological ability to reflectively carry out our life plans free from coercion and move autonomy instead to functioning as a critical indicator of whether good care is being provided.[17] Part of what will constitute good care is when such care does not

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[17] In terms of social determinants of autonomy, I have in mind here such things as social or economic power, or lack thereof, that can affect our ability to carry out decisions. Also, the higher-order reflection process critical to making informed

compromise the autonomy of the care-giver.[18] As well, good care is provided when we recognize that not all persons who need care are autonomous; in fact, people usually need care because they are not yet fully autonomous (i.e., children), have lost the capacity to be autonomous (i.e., persons with severe dementia), or will never have the capacity to be fully autonomous (i.e., persons with severe developmental disabilities). The recognition that all of us have needed and likely will need care at critical junctures in our lives moves care out of the private sphere (where those who need care are often constructed as needy and dependent others) into asking how social and political institutions can best support such basic human needs throughout our lives.

A public ethic of care can also help us reconceptualize our justification of moral knowledge. Within a justice tradition, we look for knowledge foundations which, in principle, are accessible to any rational person through reason. An ethic of care reminds us that there are also social determinants of moral knowledge. Our capacity for reflection and perhaps even our motivation to act on our reflective judgments depends heavily upon the moral education we received. Too exclusive a focus on moral knowledge as adult reflectors renders invisible the moral training we received as children. It also contributes to the ideology that rational individual reflection guarantees the truth of one's judgments. In fact, individual reflection coupled with social power structures can often reify, rather than challenge, existing

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decisions in standard accounts of autonomy is also a social product, dependent upon caring interactions with others who challenge us to think critically and reflectively (Clement, 1996).

[18] This is discussed in more detail shortly in the context of developing a framework for analysis of extending care to elder care programs and policies.

inequities. Subsequently, an ethic of care's emphasis upon social determinants of moral knowledge can supplement the rational reflection characteristic of an ethic of justice.

While a public ethic of care can help us better consider human differences, notions of moral and personal autonomy, and how we justify moral knowledge, specific considerations of an ethic of care beyond private relationships are difficult to find. Fisher and Tronto's (1990) work in articulating a 'feminist' ethic of care (in contrast to a 'feminine' ethic of care) lays a foundation from which others have worked to defend the usefulness of an ethic of care into the public sector. Tronto's (1994) discussion of moral boundaries, in which she argues that an ethic of care needs to be freed from its gendered and privatized contexts and placed within a liberal, democratic society, effectively moves beyond earlier conceptions of an ethic of care as a 'feminine' ethic. Yet specific applications of her ethic of care, beyond suggestive references to social and political concerns, are missing. Clement (1996), working from Tronto's earlier work, focuses more intentionally upon resolving problems with autonomy and with the public-private dichotomy that Gilligan's work and other 'feminine' ethics of care presents. In one chapter, Clement discusses two possible public applications of care: Ruddick's maternal pacifism and public provision of elder care. These applications, while stimulating as possibilities, are nonetheless limited to sharing one chapter, and thus are superficial in their analyses. Sevenhuijsen (1998) considers a public ethic of care with respect to two issues: the Dutch public debate on child custody, and a case study of the Dutch *Choices in health care* policy document of 1991. Working from Fisher and Tronto's framework of an ethic of care, she places an ethic of care within a postmodern moral and political framework, analyzing both social practices and moral discourses within policy documents.

All of these authors are committed to understanding an ethic of care that challenges and transcends traditional boundaries between moral and political life, between abstract and concrete moral orientations, between individualistic and relational conceptions of the self, between priorities of equality and relationships, and between fixed gender constraints. None of these thinkers affirms an ethic of care as a feminine ethic. None of these thinkers wishes to assimilate an ethic of care into an ethic of justice. None of these thinkers argue that an ethic of care is superior to or can replace an ethic of justice, and all would agree that both ethics are required for a complete account of moral reasoning. It is upon these normative assumptions about an ethic of care that this dissertation begins, with the hope of extending an ethic of care's utility into the public sphere.

<u>Defining a public ethic of care</u>: Thus far, a working definition of care and an ethic of care, with its attending phases and ethical components, have been broadly articulated. Possible contributions that a public ethic of care can make have also been identified. Exactly what a public ethic of care is, however, needs more careful attention. Although such language is frequently used, its understandings are assumed rather than made explicit. O'Neill captures this when she writes:

> While phrases such as "caring society," "community care," or "commitment to care" have become clichés of contemporary public debate, its relations to justice and its import in a world of mediated social relations where need and

> poverty are often at a distance from those who could reduce them, have not yet been convincingly elaborated (O'Neill, 1992, p. 136).

Consequently, it is important to more carefully consider the constitutive elements of a public ethic of care. In particular, the idea of a public ethic of care as it works itself out in public and organizational policies is considered.

In some respects it is easier to identify what a public ethic of care is not rather than what it is. As used here, a public ethic of care is not intended to evoke a recovery of traditional family values with its attending attachments to the naturalness of heterosexual two-parent family structures and a willingness on the part of women to sacrifice for their families and their communities (Sevenhuijsen, 1998). Conservative "family values" ideology is, in fact, antithetical to a public ethic of care.[19] Within such an ideology, families are expected to take care of their own and avoid being a burden to others; the burden of care falls to an invisible and marginalized women's culture. People who fail to provide such care are viewed as failures (Gill and Ingman, 1994). At the policy level, public policies that flow from this ideology focus on the individual or the family as the problem, and individualistic strategies are identified to intervene. "Good government" is government that stays out of private family life. Within the ideology of conservative family values, attempts to formalize care-giving with more government support are understood as leading to the disintegration of the modern family as it allows women to abandon their historically prescribed care-giving roles and further erodes men's dominance as

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[19] The term "ideology" is understood, borrowing from Abramovitz (1988), as a relatively lucid set of beliefs and values about human nature and social life generated by a society for itself.

heads of households (Binney and Estes, 1988). This understanding of a public ethic of care maintains the illusion of the family as a private domain, and continues to present the traditional family as responsible for dependents and a gender-based division of labor as normal; consequently it is rejected as a basis for a public ethic of care.

Nor is a public ethic of care simply a large aggregate of caring individuals or volunteers who work tirelessly on valued community projects. Such an understanding of a public ethic of care is, in fact, dangerous as it romanticizes the potential of volunteers to address large-scale social problems and "legitimates minimal public activity in the private sphere of the family" (Hooyman and Gonyea, 1995, p. 188). While the United States has a large nonprofit sector, it has the lowest level of public social welfare expenditures, and recent polls suggests that fewer and fewer people believe that government has responsibilities to care for those who cannot care for themselves.[20] Directors of non-profit organizations, for instance, are fearful that the increased reliance on private, voluntary, nongovernmental entities will leave many without needed services, and will become an excuse for disregarding difficult social problems (Salamon and Anheir, 1995). Rhetoric that encourages communities to take care of their own, while appealing in terms of the potential for delivering responsive care to particular individuals at the local level, is particularly dangerous to poor communities. Because 85 to 90 percent of charitable donations are

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[20] Rauner (2000), referencing the Independent Sector's Gallup Poll on giving and volunteering, notes that in 1988, 81.3 percent of respondents agreed with the statement, "Government has responsibility to take care of people who can't take care of themselves." In 1996, 60.1 percent of respondents agreed with that statement, a decline of 25 percent.

raised and spent locally, communities most in need often are not able to generate the needed funds (Wolpert, 1995). The result is a myopic sort of community caring, where those communities already advantaged by resources of time and finances are able to care for their own, but unable or unwilling to extend their resources to those distant from themselves. Truly effective community care for vulnerable populations depends upon effective care for communities-at-large in which "public policies strengthen the overall social and economic context, including income and educational resources, within which both formal and informal services provide care" (Hooyman and Gonyea, 1995, p. 189).

Neither is a public ethic of care a form of what Tronto (1994) calls 'morality first' views. Rather than understanding morality and politics as a set of congruent and interrelated ideas, 'morality first' arguments assert the primacy of certain moral values; once these moral values are fixed, then thoughtful thinkers will be able to suggest how political life should be organized to conform to these values.[21] In such a scenario, the content of care as a moral practice would first be worked out and then imported into the social and political order. This is inadequate, says Tronto, as on its own, care cannot deal sufficiently with problems of distance, inequality, and privilege. Noddings' anti-proceduralism streak and her refusal to consider any institutional or structural dimensions to care, for instance, is precarious. To assume

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[21] Tronto suggests that most contemporary liberal political philosophers fall into the 'morality first' camp, in contrast to the "politics first" view wherein political thinkers assert the primacy of political values first, and then introduce moral values into politics in accordance with the requirements of these political ideas. John Rawls' ideas stand as an examplar of the 'morality first' view in that he does not describe how the moral principles he delineates should be made into political reality.

that attentive listening and responding, as underrated as it is in terms of importance, could prevent domestic violence ignores structural determinants of such; to assume that procedural legal rules could be displaced by listening and responding ignores that such rules were put in place to prevent courts from privileging the powerful and dismissing the powerless. Similarly, Fox-Genovese uses an ethic of care on its own, says Tronto, to negate rights and advance romanticized notions of communitarianism. The danger here is that care-givers see the world only from their own perspective, stifling diversity and fostering paternalism. Finally, to understand a public ethic of care as some form of a 'morality first' argument is to reinforce the boundary between morality and political life which, along with the moral point of view boundary and boundaries between private and political life, keeps us from understanding how care can inform public life.

The notion of a public ethic of care, then, is not captured by importing unmediated ideas of care into public life, or by equating caring sectors of community life or traditional thinking of family values with a public ethic of care. How then to understand a public ethic of care? What assumptions undergird a public ethic of care? How are these assumptions operationalized as a public ethic of care in terms of public and organizational policy?

As a moral value, a public ethic of care seeks to assure good care to all members of society. Such an ethic values the daily caring of people for each other and requires us "to recognize care as a national social value rightfully calling on Americans for meaningful support as a matter of high priority . . . as a primary principle of our common life, along with the assurance of liberty, equality, and justice" (Harrington, 1999, p. 44, 48). As such, "it is not a parochial concern of women, a type of secondary moral question, or the work of the least well off in society" . . . "but a central concern of human life" (Tronto, 1994, p. 180). As a moral value, a public ethic of care suggests that our political judgments are tempered by attentiveness, compassion, and empathy just as they are already tempered by the language of rights, duties, and decisions about obligations made impartially from a distance to transcend individual points of view (Sevenhuijsen, 1998).

The assumptions that undergird a public ethic of care provide a different starting point for understanding human relationships and human nature. The starting point for understanding human interaction is not from the assumption that humans are autonomous and self-sufficient but rather interdependent; all of us are dependent for some time before becoming autonomous, and many of us are dependent on others before we die. In between, we experience times when we are more, rather than less, autonomous, but even during those times, we can be dependent in some areas of our lives. In other words, autonomy and dependence is not an either/or proposition, as Tronto (1994) suggests liberal theory sometimes implies; it is not assumed that the "normal person" is autonomous or self-sufficient. And, just as we recognize that not everyone is always autonomous, we also recognize that in spite of a democratic goal of equality, not everyone is equal. Consequently, not only can questions about how best to further interdependence be raised but also questions about how best to further equality.[22]

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[22] Is equality, for instance, furthered for women when the majority of care work falls to them via public policies that do not take the meeting of needs as a starting point?

In addition to the assumption of interdependence undergirding a public ethic of care, the presumed dichotomy between public and private spheres, including their gendered contexts, is challenged (Tronto, 1994). In particular, our notions of citizens as paid workers and producers is broadened. "Citizenly" activities are not only those activities that occur in the public sphere but in the private as well. Caring practices, historically assigned to the private sphere, are recognized as essential and valuable to keep society functioning well.[23] Thus the responsibilities that attach to caring practices are recognized as belonging to the entire society, not just specific individuals. Within a public ethic of care, the "personal troubles of the milieu" are recognized as "public issues of social structure" (Mills, 1959, p. 8).

While the moral value and assumptions of a public ethic of care constitute important starting points, this alone is not sufficient to support a public ethic of care. Stone (2000c), speaking to this link, says:

> Caring for each other is the most basic form of civic participation. We learn to care in families, and we enlarge our communities of concern as we mature. Caring is the essential democratic act, the prerequisite to voting, joining associations, attending meetings, holding office and all the other ways we sustain democracy. Care, the noun, requires families and workers who care, the verb. Caring, the activity, breeds caring, the attitude, and caring the attitude, seeds caring the politics (p. 15).

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[23] Some might argue that the state and the market, both public auspices, are involved in providing care. Both, however, as discussed later, treat the provision of adequate care as essentially a private matter.

Translating the assumptions of a public ethic of care to the practice of a public ethic of care is no small task. Tronto argues that a political context is needed to support an ethic of care; otherwise care remains gendered and private (1994).[24] In fact, it is only by understanding an ethic of care as a political idea that care can take on the transformative power that Tronto attaches to it.[25] Not only does a political ethic of care begin with different assumptions of human nature, it can inform the practices of democratic citizenship.[26] Attentiveness, for instance, will recognize that some groups are marginalized because of lack of access to needed resources. Discussions of responsibility for groups distant from the majority (either in terms of physical distance or privilege) can be brought to the foreground. Public or organizational policies that result in incompetent care practices can be challenged. The responses of those at the receiving end of care become essential for developing and evaluating policies that affect them.

Furthermore, care as a political ideal provides a critical standpoint to reveal relations of power and privilege (Tronto, 1994; Harrington, 1999; Sevenhuijsen,

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[24] In arguing that a political context is needed to support in ethic of care, Tronto (1994) returns to Jane Addams and her pacifism. Even though pacifism was consistent with the arguments Addams made prior to World War I about women's morality, and even though she was lauded for her previous work, this view was not accepted as legitimate "when it came time to return to the main action of politics" (p. 5). Politics shapes how seriously arguments are taken; Addams was unable to import her pacifism, cloaked in women's morality, into the public sphere.

[25] By understanding care as a political idea, Tronto does not face, she claims, the problem mentioned earlier of "morality first" views, that is, of bringing a moral concept into the political sphere.

[26] Although Tronto uses the phrase "a political ethic of care" in *Moral Boundaries* (1994), she does not define it per her own admission (Email conversation, November 14, 2000). Her understanding of it, however, per email conversation, is embedded in what I use as a working definition of a public ethic of care.

1998). When we ask questions, for instance, about who cares for whom, and how adequate care is, we are able to quickly see where structures of power and privilege exist. And because care work and care adequacy is concrete, experiential, and inclusive of all groups of people, it provides opportunities for those who are often disenfranchised from the political process to become involved. Piven and Cloward (1977), in their analysis of the history of social movements within the United States, remind us that "for a protest movement to arise out of these traumas of daily life, people have to perceive the deprivation and disorganization they experience as both wrong, and subject to redress" (p. 12). They need to recognize that the social institutions that that shape their experiences are not natural but artificial, created by human actors.

Stone's (2000c) argument for a "care movement" is a fitting application of Piven and Cloward's analysis and begins to provide a glimpse of what a public ethic of care looks like. Arguing that care-giving is a class issue, a labor issue, and a social welfare issue, Stone highlights the right to give care and receive care. Specifically, says Stone, families must be permitted and helped to care for their members if they wish to do so, paid care-givers must be given resources to provide humane and high-quality care without compromising their own well-being, and people who need care must be able to receive it. Joining the three corners of this triangle is already underway in a multitude of grass-roots movements which provide models for a grander care movement. Such smaller movements "demonstrate the breadth of care as a political issue and the power of coalitions to put care on the public agenda. Above all, they prove the force of caring as a motive for political action" (p. 15).

A public ethic of care, then, will draw upon certain foundational assumptions about human nature, about the relationship of private and public spheres to each other, and who and what counts as citizens and valued citizen activities. It will affirm care as a central moral value in the public square alongside of equality and liberty. It will ground care in a political context. A public ethic of care will also suggest a number of benchmarks for public and organizational policy that flow from and are congruent with the assumptions and context of a public ethic of care. These evaluative criteria recognize that care, or lack of it, is expressed in social and institutional contexts, and that if we wish to reflect the value that care is a central concern of human life, then we must change the structures and institutions through which care is reflected. These benchmarks, while discussed separately, are not discrete and disconnected points; taken as a whole, they work toward articulating criteria that can be used to assess public and organizational policy as applications of a public ethic of care. Nor are these benchmarks fully developed here; in the context of long-term care they are revisited later.

The policies that flow from a public ethic of care will begin with a public discussion of needs, grounded in the experiences and perceptions of those giving and receiving care. This is a complicated criterion, with several strands. Given an ethic of care's emphasis upon interdependence between persons and a commitment to maintaining relationships, the equality-difference dilemma is challenged by noting that difference is a property of a relationship, not a person.[27] Often, those who are

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[27] Recall the earlier discussion distinguishing an ethic of care from an ethic of justice, where the latter prioritizes some form of equality that recognizes the precept of treating like cases alike.

different, that is, those who need assistance with care, become problems because of their differences as defined by those with power and position. But in fact, if we look at the relationships between those who need care and those whom we perceive to be independent, we find that those who have power and privilege often enjoy care from those we think of as needing care, that is, the poor are employed to serve the rich. Both groups need for care but only one group has the financial resources to purchase care for themselves and their families; the care they purchase comes from devalued sources, usually women and in particular, women of color. By recognizing that all of us need care at various points in our lives, a public ethic of care moves care from the market arena, where care becomes an option only for some, to the public square, where a discussion can begin about "a public responsibility to guarantee a minimal level of services to all citizens as a public good in which all citizens should participate without undue burden" (Hooyman and Gonyea, 1995, p. 330).

Grounding a public ethic of care in a public discussion of needs, beyond challenging the equality-difference dilemma, points to a process of determining needs. We should be wary of decisions made by those some distance from concrete care-giving situations, usually elites who, no matter how well-intentioned, cannot represent the life experiences of persons with little money or little power. Policy development must include the people whose lives are affected by the outcomes, and the inclusion of the ideas of these participants must be the raw material for whatever emerges formally. Sociologist Lisa Dodson (1998), in her analysis of care work of younger siblings performed by young girls growing up in poor families, concludes that "before the policy priorities are determined, before the reforms, investments, and programs are agreed upon, the people who will live with the policy consequences must be at the table. And they must be there from the beginning, not brought in for the photographers after all the decisions are made" (p. 220). Similarly, Sevenhuijsen (1998) notes that an ethic of care is well-suited for deliberative discussions. Such conversations assume that people recognize and treat others as different and unique, and take into account their perceptions and life experiences; such discussions also recognize, however, that needs and narratives are not absolutes but understood and judged in specific contexts of action.

The policies that flow from a public ethic of care will also allow for a contextual approach to care giving and care receiving.[28] Those closest to the practice of care - - care-givers and care-receivers - - must be able to work together in such a way that responsive and competent care is realized. Implicit in this is the idea that care-givers and care-receivers must be able to define what kinds of care they most value; such assessments may well move beyond, or perhaps even exclude, life-prolonging medical interventions and include support for social services. Families must have choices about how best to care for loved ones based upon realistic assessments of the needs of care-givers and care-receivers. Organizations must have institutionalized practices that foster effective care. They must, for instance, have mechanisms through which care-givers' and care receivers' expertise can be heard and valued, and procedures in which adaptations for care practice based on these

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[28] Recall the earlier discussion distinguishing an ethic of care from an ethic of justice where the latter is characterized by abstracting oneself from the particular aspects of a situation to see who it comes under a general rule, and where reason is privileged as a way of knowing.

expert recommendations can be made quickly. At the level of public policy, sufficient latitude must be offered to organizations to deliver care in ways that best reflect the needs of all citizens. Funding cycles should follow stringent outcome evaluations of care based upon care-giver and care-receiver assessment, in the context of a democratic discussion needs. In short, flexible policies and programs would be created so that different notions of what constitutes good care can flourish.

Third, the policies that flow from a public ethic of care will affirm a social conception of the self.[29] As Tronto (1994) argues: "A society that took caring seriously would engage in a discussion of the issues of public life from a vision not of autonomous, equal, rational actors each pursing separate ends, but from a vision of interdependent actors, each of whom needs and provides care in a variety of ways and each of whom has other interests and pursuits that exist outside the realm of care" (p. 168). If we focus on relationships between individuals (rather than the boundaries around them), we see that it is not enough to ask who deserves how much of what; we must also think carefully about how policies shape and define relationships. We might ask, for instance, whether a particular policy promotes care for citizens as citizens, or whether it stigmatizes and further divides people by their neediness. Can we recognize the need for long-term care as a normal risk of living and provide a system of care such that when citizens need it, they can get it, without stigma of welfare or fear of impoverishment?

Relatedly, policies that affirm a social conception of the self would consider carefully how public and organizational policies shape and define the problem of care. Is the provision of good care considered an individual or family problem, and policies are designed to intervene at this individual level within the private life of the family, or is the provision of good care understood as a societal responsibility? A public ethic of care requires collective responsibility for protecting the welfare of vulnerable groups, including those who do the work of care. This collective responsibility should be apparent in how we intervene with care-givers and care receivers, and this should be apparent in our means of financing care. Wiener and Illston (1994) suggest that "coverage of long-term care on a nonmeans-tested basis will go a long way toward treating disability as a normal risk of life rather than the failure of the individual deserving of public charity through welfare" (1994, p. 407). In short, a public ethic of care requires structural change such that a stronger public or governmental presence ensures a comprehensive range of social, economic, work-related, and medical services to support, rather than exploit, care work.

Finally, policies that flow from a public ethic of care must be firmly grounded in a liberal, democratic, pluralistic society. The nature of care lends itself to two very large dangers, criticisms that have been made earlier about some forms of an ethic of care. First, care can easily become maternalistic/paternalistic. Care arises out of the fact that not all of us, at all times, are equally able to care for ourselves and be autonomous. In concrete care-giving situations, as well as at the level of policy work, those charged with the responsibility of care work can easily assume a posture of being experts in charge, of knowing what is best. In doing so, they infantalize the

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[29] Recall the earlier discussion distinguishing an ethic of care from an ethic of justice where the latter is based on assumptions of human separateness.

care receiver or construct that person as pitiful and needy, giving rise to even more profound issues of inequality. Second, care can become parochial. In the intensity of care-giving practices, it is easy for care-givers to come to see the carework they do as the most important work to be done. There are no guarantees that people involved in such relationships will extend themselves from their current carework to notice, for instance, that other frail elders or small children in this country and beyond need care. The solution to these problems, suggests Tronto (1994) "is to insist that care needs to be connected to a theory of justice and to be relentlessly democratic in its disposition" (p. 174).

To make care democratic, it must focus on needs and it must consider the distribution of care work in society (Tronto, 1994). A public discussion of needs was briefly considered earlier. The recognition that all of us at need care at various points in our lives can move our discussion out of the marketplace where such needs become commodities that only a few can afford to have met, and out of means-tested welfare programs where those with care needs are stigmatized, into the public square. Here open negotiations can occur about precisely what citizen needs for care are over the course of lifetimes, and how best to allocate resources. Because care work is often cashed out along the lines of gender, ethnicity, and class, just care must also consider whether and how care-giving might be more equitably distributed and reimbursed. Care-giving that compromises the autonomy of either the care-giver or care-receiver, for instance, is not just care. Clement (1996) suggests better and worse public applications of an ethic of care are mediated by the extent to which autonomy is preserved. Furthermore, there is surely something unjust about earning an income as a care-giver that puts one barely above the poverty line, if it indeed it does even this, and distributing such work to those who, historically, have been largely excluded from the political process.

A public ethic of care, then, will be evident in public and organizational policy to the extent that such policies are grounded in a public discussion of needs in which the experiences and perceptions of those giving and receiving care are taken seriously, to the extent that they allow for a contextual approach to care-giving and care-receiving, to the extent that they affirm a social conception of the self, and to the extent that care needs are connected to a theory of justice and are democratic in nature. Following Kamerman and Kahn's "family impact analysis (1989), these benchmarks can be used as the basis for a care impact analysis in regards to long-term care policy for the elderly. As these criteria become operationalized in policy, the commitment to integrating care as central force in shaping society is reinforced. Not only do the assumptions of an ethic of care shape public policy, but public policy grounded in an ethic of care continues to influence our behavior and assumptions about care as a critical variable for public concern.

A public ethic of care for long term care: Long-term care for frail elders is used here as an examplar through which to consider a public ethic of care. This focus is selected for three reasons. First, long-term care is an important sub-field in gerontology and an important field of practice for social work. Applications gleaned here regarding a public ethic of care can be further considered in other social work fields of practice. Second, long-term care concerns illuminate important dimensions of a public ethic of care and has the potential to raise and consider critical challenges to the usefulness of an ethic of care. These challenges include, for instance, such themes as the gendered construction of care-givers as women, the allocation of care's financial obligations to family, market, and public spheres, and the usefulness of an ethic of care to resolving difficult rationing, prioritization, and allocation questions in regards to the social and physical needs of the elderly. Third, an ethic of care's attention to issues of vulnerability, dependency, and "otherness" are congruent with concerns faced by the elderly, their care-givers, and society as a whole. This is not to homogenize elders as a vulnerable and dependent population. Yet on whole, as people age, their need for care increases.

Several questions form the framework for an analysis of a public ethic of care in regards to long-term care. These questions are:

1. What problems exist within long-term care that lead us to conclude that a public ethic of care is necessary?
2. In what ways, if any, does current long-term care provision take seriously (implicitly or explicitly) Fisher and Tronto's (1990) conceptualization of care and the ethical components which attach to this definition: caring about and attentiveness to needs; taking care of and responsibility; care-giving and competence; and care-receiving and responsiveness.
3. What tensions are created and/or persist within programs and policies given commitments to a public ethic of care?
4. How could an intentional commitment to a social and political ethic of care shape public long-term care policy and the programs and services which

develop from these? What are the implications for public policy if care were affirmed as a more central moral focus?

This framework will be considered in regards to particular programs and policies which shape long-term care, to the historical and social factors that shape these programs and policies, to the explicit or implicit assumptions and normative dimensions of care in these programs and policies, and to the practices that emerge from these. It is hoped that by using care as an explicit category of analysis, it can serve as a basis for reformulating established normative concepts that are used as program and policy guidelines in these broad arenas. With an understanding of what constitutes a public ethic of care, and with the understanding that this ethic is not confined to the private sphere, to women, or intended to replace or be replaced by an ethic of justice, we turn to the work of assessing and evaluating a public ethic of care in long-term care.

PART TWO
EVALUATING LONG-TERM CARE
INFORMED BY A PUBLIC ETHIC OF CARE

Chapter Four
Caring about and caring for:
An evaluation of our current long-term care system

One does not need a public ethic of care to identify the limitations of and short-comings in long-term care as these are well-documented in the professional literature. The first chapter identified several overarching problems in long – term care for frail elders. These included funding issues, fragmentation within and lack of coordination between available services, lack of access to services for some creating a no – care zone, lack of fit between the perceived needs of frail elders and available funding streams and service provisions, care worker concerns, and quality of care concerns. Using an ethic of care as an analytic tool, however, can inform the way in which long-term care for frail elders is organized and delivered, both in terms of current shortcomings and in terms of possibilities for revision where care becomes a central social and political construct. Part II undertakes this evaluation and reconceptualization task. Chapter Four, using Tronto's phases of caring about and caring for, and chapter Five, using the phases of care giving and care receiving, analyzes our current arrangements of long-term care.

Caring About and Attentiveness to Needs

The first phase of caring about requires becoming aware of and paying attention to the need for caring. Caring about recognizes that caring is necessary and that a need for caring exists; in fact, the starting point for care is to take seriously the needs of others.[1] To care about someone, or some group, or some issue requires "listening to articulated needs, recognizing unspoken needs, distinguishing among and deciding which needs to care about" (Tronto, 1998, p. 16). The moral aspect of caring that attaches to the phase of caring about is attentiveness. Attentiveness is required to recognize that there is a need about which to be concerned and to accurately assess perceived needs and responses to needs.

To be attentive is to notice that a population of frail elders exist whose needs are not met, only partially met, or met inappropriately. To be attentive is to notice how past and current social, economic, and political practices shape our understanding and delivery of long –term care. To be attentive is to notice how traditional understandings of human nature shape caring practices in long-term care. To be attentive is to notice long-term care issues currently on the periphery, or not at all recognized, and bring these to the center such that they can be perceived as concerns which we ought to care about. This latter type of attentiveness to what is not always noticed should be of concern particularly to social workers, who historically at least, have cared about those populations - - including the frail elderly and persons with physical and mental disabilities - - not noticed by those with power (Witkin, 1998, 2000).

The first part of this chapter argues that when long-term care for the elderly is analyzed from a public ethic of care perspective, considering the first phase of caring

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[1] To assert that the starting point for care is to take seriously the needs of others raises thorny and complex issues. In defining a public ethic of care, the suggestion was made, but not developed, that a deliberative process is needed to sort out the question of needs. This is taken up in Chapter 6.

about and attentiveness, what becomes clear is that no coherent system of long-term care exists in the U.S. nor are there any settled notions about how such a system should look. Instead, long-term care is shaped and delivered by the funding streams of a patchwork of federal and state policies designed to address concerns and problems other than meeting the needs of frail elders. The funding sources that assist most in providing long-term care - - Medicare and Medicaid - - were never intended to do so, and as such, their provisions are not always an attentive response to the long-term care needs of the elderly. Furthermore, the current overarching problems of long – term care in this country follow from and are perpetuated by lack of discussion and subsequent lack of consensus about what long-term care should be and how it can best be grounded in meeting the needs of frail elders; instead, the shape and delivery of long-term care is left to a haphazard political process and its resultant policies and funding streams.

No system of care; No settled notions: A brief excursion into the historical roots of long-term care is necessary to argue that no coherent system of long-term care exists in the U.S. and settled notions about how such a system should look are likewise absent. Although any attempt at providing historical context regarding long-term care is selective and interpretive because it is part of a much larger history of health and social welfare, some broad themes characterize the development of home care and nursing home care.[2]

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[2] There are many ways to divide the conceptual pie when speaking of long-term care. Following the conceptualization most used in the professional literature, long-term care as consisting of home care and nursing home care is used here.

Home Care: In the history of home care, there is little attention to developing a system of care based upon the stated needs of those requiring assistance. Instead, home care evolved as a response to other issues, some legitimate of course, but nevertheless, not grounded in an intentional desire to meet the needs of frail elders.

Prior to the beginning of the 20th century, most care for frail elders occurred in the home, or for those with no family or a family of limited means, the poorhouse. With the emergence of modern medicine, alongside of industrialization, urbanization, and immigration, medical care shifted from its location in the home to the offices of physicians and to hospitals. The frail elderly, however, and their admission to hospitals presented several problems. Physicians could do little to treat chronic illnesses and the voluntary hospitals "found that their beds were occupied by the incurable chronically ill despite determined efforts to screen out patients who ostensibly undermined hospital capacity to provide beds for the potentially curable." State and local governments "whose public hospitals bore the brunt of chronic care demands, " also were not pleased with increasing numbers of incurable elders living out final days in their beds (Benjamin, 1993, p. 131 – 132).[3]

The response to cost and utilization concerns, beginning already in the 1920s, was to consider alternatives to costly institutional care. Home care was seen as a possible solution to these concerns; it was not widely embraced, however, mainly because health care workers were skeptical that the less-educated and urban poor could do an adequate job (Benjamin, 1993). Furthermore, urban dwellings were

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[3] See Benjamin (1993) for an extended and thorough discussion of the history of home care.

small and poorly ventilated. Strained relations between family care-givers and care-receivers were present as well (Boas, 1930; Boas and Michelsohn, 1929). Interest in home care during the 1930s and 1940s persisted, but apart from a few selected initiatives, no planned efforts occurred to influence the growth of home care. The Old Age Assistance (OAA) program, however, did offer cash assistance to the elderly poor to help them live as independently as possible and purchase needed services. This was not intended primarily to develop home care (although it had this effect) but to empty almshouses; in fact, OAA funds could not be used for care in public institutions. Consequently frail elders in need of assistance who could no longer live in almshouses used their OAA funds to purchase the care they needed. This care was usually secured in the form of paying for boarding home care.

The introduction of a national health insurance policy proposal in 1949 set off a series of discussions in the 1950s about the role of the federal government in financing health care; these discussions eventually led to the 1965 Social Security amendments establishing Medicare and Medicaid (Marmor, 1973). Home care, however, until the late 1950s, received little attention in these discussions (U. S. Congress, 1963 – 1964). By 1961, this situation had changed: concerns about excessive hospital costs, a few visible and respected home care programs, and Blue Cross-Blue Shield's new coverage in some policies for home care brought the role of home care to the foreground in Congressional hearings on health care. Both the American Nurses Association and the American Medical Association argued that a network of home care agencies would reduce hospital and nursing home admissions and length of stays in hospitals. As they argued for medical care, social service groups argued for collaborative approaches to home care that would include homemaker services (U. S. Congress, 1961). Blue Cross-Blue Shield's experience with linking home care explicitly to hospital care assuaged fears of those within insurance circles who worried about quality and eligibility control; Blue Cross –Blue Shield's connection to the hospital, in fact, assured the exclusion of the chronically ill under home care.[4]

The process of how home care finally became included into the final Medicare amendment of 1965 receives little attention in the literature. Benjamin (1993) suggests that a small group of Social Security administrators looked for direction from two sources, the experiences of Blue Cross-Blue Shield and already existing home care programs, particularly the model Montefiore home care program in New York City (and connected to Montefiore Hospital). The final Medicare regulations were shaped by emulating Montefiore's program in conjunction with Blue Cross insurance principles.[5] Social Security Administration (SSA) officials, however, worried about Montefiore's flexible, comprehensive, and often time-lengthy services, set about imposing limits on services, required physician certification of need and

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[4] Benjamin (1993) and Follmann (1963) both note that the chronically ill were perceived by insurance companies in the 1950s as being a "bottomless pit" of needs; the Social Security administrators, in their final construction of the 1965 Medicare amendment, were also concerned about this.

[5] Montefiore's program was a post-acute program serving many elderly following hospitalization. A range of services, under a physician's plan, were provided, including house calls, nursing, social work, housekeeping, transportation, medication, and so forth. Although Social Security administrators admired Montefiore's program, they were very concerned about its orientation to the chronically ill, its willingness to provide homemaker services (which, in their minds, would lead to family members abandoning this role), and the long time period (sometimes more than two years) during which services were provided (Follmann, 1963).

plan of treatment (even though the physician was rarely in the home), and tightened eligibility rules to include only those who were home-bound and who had recently been hospitalized - - regulations that closely followed Blue Cross plans. The medical construction of home care was clear not only in its eligibility rules but also in its benefits; nursing visits, physical and occupational therapy, medical social services, home health aides, and medical supplies/appliances were available under the care and supervision of physicians. By establishing home care as an acute care, medical service controlled by physicians, SSA officials sought to demonstrate the noninflationary character of publicly financed hospital insurance and present home care as a cheaper alternative to both hospital and nursing home care (Follmann, 1963).

While the inclusion of home care benefits in the 1965 Medicare program was intentional, it was not motivated by careful attention to the needs of older persons. Instead, "it was an explicit, but primarily symbolic, component of a budgetary strategy designed to convince critics that publicly financed hospital expenditures would not go through the roof" (Benjamin, 1993, p. 138). The language of cost-savings in the context of medical care was the predominant discourse; what was left out of this picture were chronically ill frail elders whose needs for assistance could not be easily categorized into acute versus custodial care.

Although including home care benefits in the 1965 Medicare program was intentional, even if it was not motivated by explicit concern for those needing such care, homecare under the new Medicaid program in 1965 was an afterthought, argues

Benjamin (1963).[6] Medicaid discussions were dominated by larger debates between an expanded federal-state health care program as an alternative to the proposed federal health insurance bill, but home care slipped into the final amendments as an outgrowth of earlier Old Age Assistance (OAA) payments and the Kerr-Mills Act of 1960.[7] The final Medicaid amendment was an outgrowth of the Kerr-Mills Act of 1960, an earlier federal-state funding match attempt at providing health care for elderly too poor to pay for medical insurance but not poor enough to qualify for Medicaid. This Act was important to home care because it provided a wider range of services, including home care, for federal cost sharing.[8]

The deficiencies of the Kerr-Mills Act - - not all states participated in it and among those who did, coverage varied greatly - - prevented its acceptance as a model for national health insurance for the elderly, but, not surprisingly, it was deemed sufficient for the poor. The Kerr – Mills Act optional provisions for home care, however, remained in the new Medicaid legislation. Because its provision was optional rather than required, home care under Medicaid did not develop quickly; institutional care remained the default choice of care. As with the Kerr – Mills Act,

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[6] For the larger history of Medicaid, see Stevens and Stevens, 1974; Vladeck, 1980.

[7] OAA was part of the Social Security Act of 1935 and offered cash assistance to low-income elders to purchase care for oneself at home rather than live in county nursing homes. The 1950 amendments allowed for federal matching of state and local dollars to providers of heath services for OAA recipients. As discussion about hospital insurance for the elderly under Social Secruity increased in popularity during the 1950s, those opposed to such insurance attempted to present another alternative, the Kerr-Mills Act of 1960, and this was added to the Social Security amendments of that year. This Act created a new federal-state program that expanded the existing vendor payment program under OAA (Stevens and Stevens, 1974; Vladeck, 1980).

[8] The framers of the Kerr-Mill Act wanted to demonstrate the superiority of their plan over the proposed Medicare plan, and thus offered more extensive benefits (Vladeck, 1980).

health care coverage by state for Medicaid recipients was uneven, depending upon a state's commitments to the poor and/or a state's economic situation. Furthermore, because the rates of reimbursement to physicians was lower under Medicaid than Medicare or through private pay, Medicaid patients had a difficult time securing similar-quality health care services as Medicare or private pay patients.[9] As with Medicare, the predominant discourse surrounding Medicaid was one of cost-savings. Although an expanded set of home care services beyond narrowly defined medical care was included under Medicaid, these were included as part of larger political and economic maneuvers and negotiations.

With the implementation of Medicare and Medicaid and its public funds in 1965, enacted to meet the acute health care needs of the elderly and the poor, the

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[9] Interest in maintaining clear lines between the categories of "worthy" and "unworthy" poor, rather than designing a national health insurance system attentive to people' needs, was evident once again. And lest we think that race does not factor into this division, it is important to remember that the 1935 Social Security Old Age and Survivors Insurance program also made distinctions between the "worthy" and "unworthy" poor. The Social Security Act established a federal social insurance program tied to employment while Old Age Assistance, also part of the Social Security Act, provided that states could provide cash assistance to elderly poor not eligible for social insurance. The elderly poor not eligible for Social Security included agricultural and domestic workers. This was a major concern for the National Association for the Advancement of Colored People (NAACP) who protested the Southern Democrats' exclusion of such workers from Social Security. Charles Houston, board member of the NAACP, argued against Social Security before the Senate Finance Committee, asserting that while the NAACP had been inclined to testify in favor of the bill, the more it studied the bill, the more it "looked like a sieve with holes just big enough for the majority of Negroes to fall through" (Hamilton, 1994, p. 495). The NAACP was unable to garner the support it needed in Congress to include domestic and agricultural workers under the old age and unemployment compensation system. Instead, the concerns of needy domestic and agricultural workers were delegated to public assistance programs administered by the states, who had considerable freedom to implement (or not implement) Old Age Assistance programs. It is from these Old Age Assistance programs that the Kerr-Mill Act emerged, and from this, the Medicaid program.

long-term care industry grew (Vladeck, 1980). Before addressing the development of long-term care following Medicare and Medicaid enactment in 1965, the history of nursing home care is briefly considered.

Nursing home care: While home care was legitimized through perceived cost savings to institutions, nursing home care followed a slightly different trajectory. Nevertheless, here as well, guiding principles were not explicitly grounded in caring about a frail population. While caring for the elderly in the home (and anyone else in need because of poverty or illness) was the norm during the Colonial period, in the decades after the Revolution the rise of almshouses occurred. Inspired by the Quincy Report (1821) and the Yates Report (1824), both of which located the causes of poverty within individuals' lack of moral sturdiness, almshouses grew quickly in numbers. They were designed to reform and punish the poor, and also serve as a deterrent to further poverty-causing behavior. The poor conditions served a more subtle goal as well, one of encouraging family members to care for their own lest a family member be sent to the poor house (Katz, 1984).

Although almshouses were not designed intentionally for the elderly, those who were poor, ill, and without family eventually landed in such placements, as no categorical distinctions were made between the aged, the sick, the mentally ill, and so forth. As social reform efforts increased in the mid-1800s, however, resulting in specific institutions for specific populations, the elderly were left behind in the almshouses. Because they were poor, often foreign-born, and because medicine offered no cures for old age, designing special institutions for the "unredeemable" elderly seemed futile (Haber and Gratton, 1993). Thus institutional care in poor houses became the default location of residence for the poor elderly in the 1800s, and inadequate care was deemed acceptable (Vladeck, 1980).[10]

By the late 1800s, poorhouses were symbols of brutality and corruption (Cole, 1992). As such, they were noticed by some as arenas for reform. Challenging the notion that the elderly poor were poor because of their own moral impoverishment, reform efforts focused on changing the perceptions of the public toward the causes of poverty among the elderly. Renewed understandings that advanced age, not lack of virtue, could result in poverty even among the most hard-working citizens emerged, and thus efforts were made to improve the quality of care in almshouses. By the 1920s, the prevailing idea that care for indigent elderly could best occur in public almshouses was challenged, primarily because of rising costs of such care - - a theme common to the rise of home health care. And in spite of best efforts to keep the chronically ill out of acute care hospitals, hospitals still cared for a growing number in their wards.

Although it was thought that economic stability and a dependable source of income, such as Social Security pensions, would reduce the needs for public almshouses, this goal was not realized. Poverty and care needs for chronic illness persisted, even with Social Security pensions, and from this, the modern nursing home industry developed (Vladeck, 1980). From 1935 to 1975, nursing homes

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[10] By the mid to late 1800s, benevolent care facilities for specific populations sponsored by voluntary organizations began to emerge. These "Homes for the Aged" were associated with particular religious, civic, or occupational organizations. In general, the quality of care in these facilities for members of a particular subgroup was very good. Of course, not all frail elders could access these homes (Boondas, 1991).

continued to develop but not through intentional policy initiatives and not through intentional and explicit attention to the needs of the elderly. Although the Social Security Act of 1935 did not contain health care provisions, the Old Age Assistance (OAA) program, through state and federal dollars, did provide funds to aged poor not living in public nursing homes to purchase services they might need for their care. The unintended consequences of this policy (that tried to address poverty without addressing chronic care needs) ironically stimulated the growth of the commercial nursing home industry. Chronically ill and poor elders, with no other means of care, used their OAA funds for payment in proprietary and voluntary nursing homes, then frequently referred to as "rest homes" or "homes for the aged."[11] Although public almshouses decreased in population by ten percent during the 1930s, the number of older persons living in homes for the aged increased by 38 percent (Holstein and Cole, 1996).

Several initiatives during the 1950s also contributed inadvertently to the continued rise of nursing home care.[12] In 1950, Congress authorized matching funds to states through vendor payments for services rendered to the aged poor and the permanently and totally disabled living in nursing homes. This vendor system and the funds it provided made the nursing home business attractive to investors and business entrepreneurs, and gave the newly organized nursing home lobby a specific federal agency with whom to negotiate payment rates and regulations. Hawes and

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[11] These homes resembled board-and-care homes, not modern nursing homes, and varied greatly in the quality of care.

[12] The legislative history of these initiatives is complex and beyond the intent of this chapter.

Phillips (1986) note that the vendor payments "thus shaped a system in which the cost, quality, and level of services are decided in a transaction between vendors (providers) and the state, creating the politics of long-term care" (p. 495). Also, the 1954 Medical Facilities Survey and Construction Act, an amendment to the Hill-Burton Act, provided construction grants to nonprofit homes and other nonproprietary long-term care facilities. This not only increased the number of beds available, but shaped the medical design of these facilities because of its requirement that such facilities be affiliated with a hospital and be built according to certain specifications that resembled small medical institutions. Finally, because Hill-Burton excluded proprietary agencies, and in response to lobbying from the American Association of Nursing Homes, Congress authorized two additional loan programs. The Small Business Administration (SBA) was able to make direct loans to proprietary nursing homes while the Federal Housing Administration (FHA) offered loan guarantees for up to 90 percent of construction costs for new nursing homes. The net effect of these Congressional authorizations propelled the development of a freestanding industry quite separate from other medical care institutions, although they eventually also became more medicalized in response to funding streams that required the provision of "skilled nursing" care.[13]

Nursing home care covered by Medicare and Medicaid, limited to postacute convalescent care, was initiated because of cost concerns in acute care hospitals.

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[13] The repercussions of these federal initiatives for African Americans were severe. Following existing patterns of segregation, African Americans were directed toward overcrowded county facilities, unregulated boarding homes, and state-run mental institutions. Even Medicare and Medicaid did not substantively alter these patterns of discrimination (Smith, 1979).

Under Medicare and Medicaid, reimbursements methods were modeled after private insurance, that is, based on retrospective payment according to incurred costs. This structure provided a strong impetus for maximizing the volume of public health care, and inflationary health care expenditures, particularly for hospital charges, emerged immediately. Despite demonstration projects with alternative reimbursement methods and voluntary attempts at cost containment, Medicare and Medicaid costs escalated. In spite of tight regulations governing Medicare reimbursements to nursing homes, Medicare nursing home costs quickly exceeded anticipated costs. By 1969, Medicare rules were tightened to include only those patients with the potential for rehabilitiation, effectively ruling out payments for the terminally ill. Medicare was directed to "err on the side of denying rather than approving benefits" (Vladeck, 1980, p. 57). Medicare was reaffirmed as a medical benefit, not as support for custodial care. Medicaid became the most important source of federal support for care in skilled nursing facilities (and later intermediate care facilities), although this was done with little planning of program design.[14] Vendor payments continued, and costs continued to escalate, often for care that was sub-standard (Kane, Kane, and Ladd; 1998; Vladeck, 1980). Skilled nursing facilities that did not meet the standards for skilled facilities became intermediate care facilities. These facilities reached

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[14] Skilled nursing facilities provide 24-hour continuous nursing care. Registered nurses, licensced practical nurses, and nurse aides deliver services prescribed by a physician. Emphasis is placed on medical nursing care; restorative, physical, occupational and other therapies might be included. Intermediate skilled facilities, in addition to room and board, provide regular medical, nursing, and rehabilitative services to persons not capable of independent living, but not as seriously ill as those requiring a skilled nursing facility (Fabiano and Martyn, 1998).

capacity not only by an increasing elderly population but because large state mental institutions, following the Medicaid funding stream, transferred their patients here.

In short, the development of long-term care up to and immediately following the enactment of Medicare and Medicaid is characterized by two themes. First, long-term care developed "haphazardly" (Holstein and Cole, 1996, p. 42), without benefit of sustained discussions among key stakeholders, particularly those in need of such care. Instead, long-term care emerged to address other concerns: public perceptions of hospitals as places where people die, overcrowding and high costs of acute care hospitals, poverty, and so forth. Second, the policies that emerged were "an afterthought, a side effect of decisions directed at other problems" (Vladeck, 1980, p. 31). Polices were developed in a piece-meal fashion with little coordination or attention to consequences, and not guided by an overall vision of what needed to happen to meet the needs of the frail elderly. Instead, solutions targeted specific problems, while the circumstances that gave rise to problems were ignored: "Policy debates [were] regularly informed by ideas about how best to correct the perceived imperfections of past policy, rather than simply how best to respond to social conditions as such" (Orloff, 1988, p. 42).

Holstein and Cole conclude that "neither Medicare nor Medicaid responded adequately to the growing burden of chronic illness care" (1996, p. 40). In defense of these programs, however, they were never intended to address such care. The architects of Medicare saw their initiatives as responding to problems of health care for elderly persons who had worked during their adult lives (the "worthy" elderly) and now were in danger of impoverishment due to poor health.[15] Medicaid was intended to be a means-tested health care insurance program for the poor, regardless of age. The crafters of Medicare and Medicaid saw the meeting of custodial needs as belonging to the welfare system; what they missed was that there is not a bright line between custodial and medical needs. Furthermore, even though one could argue that meeting custodial needs belongs to the welfare system, this system had few resources for meeting needs.

Form follows Funding: The familiar axiom in policy analysis that form follows funding is apparent when analyzing long-term care initiatives. Federal and state policies drive the shape and delivery of services; long- term care has not been driven by careful attention to the needs of those who require long-term care. The evidence for this is seen in the discussion above that analyzes the haphazard way in which long-term care has emerged. Policy funding provisions in regards to almshouses, Old Age Assistance payments, the Hill-Burton, federal loans to the proprietary sector, Medicare, and Medicaid, to name only a few, have shaped the implementation and delivery of long-term care; as well, the motivations behind these policies and programs were not primarily ones of responding to the needs of frail elders. This becomes even more clear as we consider policy initiatives that emerged

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[15] Several other agendas were also at work with Medicare, all complex and intricate stories on their own. For some, such as Wilbur Cohen, the development of Medicare held promise for being a first step toward universal national health insurance. The elderly were a popular group with whom to begin because they were not covered by voluntary insurance and their needs for hospital care were easy to document (Brown, 1996). Also, hospitals were in desperate need of funds for further research and technology development, and the proposals leading to Medicare often included providing income to hospitals (Stevens, 1996).

during the 1980s and 1990s, particularly the implementation of the Prospective Payment System (PPS) and related Diagnostic Related Groups (DRGs) in the 1980s and the Balanced Budget Act (BBA) of 1997. These policies have been credited with being among the most significant pieces of health care legislation since the enactment of Medicare and Medicaid in 1965 (Estes, 2000; Ettinger, 1998; Gladieux, 1999; Hafkenshiel, 1997) and consequently, it is instructive to analyze these through the lens of "caring about" the needs of frail elders.

The 1980s - - PPS and DRGs: During the early 1980s, health policy focused intentionally on cost containment and competition to stem the rising percentage of the GDP consumed by health care.[16] The larger social, political, and economic context of the early 1980s shaped discussions of concerns raised by increasing health care costs. Politically, President Reagan's new Federalism suggested that rising health care costs were caused by too much government regulation; ideological commitments to economic principles of competition and an ethic of personal responsibility would be needed to stem these rising costs. Demographic realities, such as declines in mortality, rise in life expectancy, and continued prevalence of chronic and persistent illness pointed to the need for alternative and expanded sites of care beyond acute care settings. As well, changes in societal values and priorities, with discussions of generational equity, perceptions by some of the elderly as "greedy geezers," and revised notions of what is owed the elderly in a resource-scarce environment became heated arguments, particularly during this time of economic recession. Social

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[16] From 1980 to 1988, the rising average rate of spending for health care compared to the general price consumer index was 14.8 percent to 4.6 percent (Estes and Swan, 1993).

changes such as geographical mobility and increasing participation of women in the paid labor force raised concerns that sufficient informal care-givers would be available to care for an increased percentage of frail elders. Finally, continued concerns about emerging high cost medical technology and its ability to extend life raised both ethical and economic concerns (Estes, Swan, and Associates, 1993; Kane, Kane, and Ladd, 1998).

The government's response to rising health care costs in the early 1980s included federal deregulation policies, decentralized authority and financial support in public health and social programs, and a new tax structure based on supply-side economic policies. Reagan's new Federalism was intended to decrease the federal role in health and welfare by shifting such responsibilities to state and local levels via block grants. Although this was intended to place needed programs closer to the people, newly-granted flexibility to the states to design their own eligibility requirements, in tandem with newly opened doors for market competition in health care, left many low- and middle-income people without needed services (Bergthold, Estes, and Villanueva, 1990). Deregulation removed previously existing legal restrictions regarding for-profit health care, resulting in increases in the number of proprietary providers, chains, and other multifacility organizations.

The Prospective Payment System (PPS), implemented between 1983 and 1985 and emerging from the directives of the Tax Equity and Fiscal Responsibility Act (TEFRA), was an attempt to curb the rising costs of inpatient care in acute care hospitals by assigning admission-based payment, based upon 467 diagnosis-related groups (DRGs), to patients.[17] It was hoped that PPS incentives would decrease lengths of stay of Medicare patients, provide intensive and more focused care, cut back on non-essential services, and aim for a more cost-efficient hospital case mix. Its goal was to save dollars by shifting costs to long-term care systems. Prior to this, hospitals were reimbursed on the basis of patient costs incurred while hospitalized. There were, therefore, fiscal incentives to provide more services and invest in costly and expensive technology as these costs were passed on to third-party payers. With the passing of the PPS, financial risks for intensity of services and length of stay shifted to hospitals and physicians from third-party payers.

The effects of the PPS and DRGs upon hospital and non-hospital providers of

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[17] In addition to the PPS, other cost-containing policy initiatives consistent with Reagan's new federalism were implemented during the 1980s. In terms of Medicare, the Omnibus Reconciliation Act of 1980 (ORA) liberalized home health care by eliminating the mandatory three-day hospital requirement for Part A and the 100-visit cap under parts A and B of Medicare. ORA also eliminated restrictions on Medicare certification of proprietary home health agencies in states without licensure as well as the Part B deductible. This allowed for proprietary developments in the home health care market. Waivers permitted the provision of state-financed home health care instead of institutional long-term care for acutely ill persons. This, along with deregulation and other policies designed to promote competition, was the impetus for unprecedented growth of home health care during the 1980s.

The 1981 Omnibus Budget Reconciliation Act (OBRA) tried to promote the growth of a market-based health care sector and limit federal contributions to joint state-federal programs. Previous freedom of choice regarding providers for Medicaid beneficiaries was rescinded. These policy changes resulted in the increased growth and types of nursing homes. In 1985 there were approximately 19,000 nursing home facilities in the United States of which 75 percent were proprietary agencies. Forty-one percent of these facilities (compared to 28 percent in 1978) were owned by organizations with multiple facilities and complex systems of vertical and horizontal integration. Thirty-two corporations controlled 17 percent of nursing home beds, and many of the larger chains were publicly held corporations listed on the New York and American Stock Exchanges. As with home health services, the decade of the 1980s was a time of uncertainty and change for nursing homes due to several policy changes and interpretations (U.S. DHHS 1985, 1987; U.S. G.A.O., 1983, 1985) health and social services has been profound, credited with changing every part of the health care system (Guterman, Eggers, Riley, Green, and Terrell, 1988). For older adults in particular, the PPS shifted the locus of care for elderly and chronically ill persons from hospitals to the community. The intended goal of shorter stays in the hospital was realized almost immediately. The first year of the PPS resulted in 21 million fewer days of hospital care. The average length of stay for Medicare patients in acute care hospitals decreased 17 percent from 1984 to 1986; average length of stay in days decreased from 10.1 to 8.8 days (Guterman, Eggers, Riley, Greene, and Terrell, 1988). On the receiving end of hospital discharges, most nursing homes admitted patients directly from the hospital. Medicare patients were discharged from the hospital "sicker and quicker," and in need of more medically-intensive services (Estes, Swan, and Associates, 1993).[18] Under the PPS, nursing home referrals increased and nursing home admissions increased 23 percent from 1981 (9.6 admissions per 1000 enrollees) to 1984 (11.8 admissions per 1000 enrollees). The average length of stay decreased from 29 days in 1981 to 23 days in 1985 (a 20 percent decline), reflecting the increase of short-term residents in comparison with long-term residents. In short, the PPS drastically altered the way in which the Medicare program functioned, and its effect upon health care provision was as profound as the introduction of Medicare and Medicaid in 1965.

Not only were more people seeking care after the implementation of the PPS, the intensity of their needs for service changed. Nursing homes, home health care

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[18] There is evidence as well that in the wake of implementing the PPS, nursing home deaths increased while hospital deaths decreased (Sager, Easterling, Kindig, and Anderson, 1989).

agencies, hospices, and adult day centers indicated that people being referred for services had greater levels of disability and dependency, and higher illness acuity ratings, that is, in need more hours of care per day (Estes, Swan, and Associates, 1993; Shaugnessy and Kramer, 1990). These providers added services to their list of resources, and these tended to be medical and high-technology services rather than social or supportive services for the chronically ill.[19] In general, less profitable and less reimbursable services, such as social and custodial care services, were cut or eliminated, thus effectively narrowing the spectrum of services included previously under the umbrella of long-term care.

In addition to increases in the number of persons seeking services after the implementation of the PPS, most of whom were seeking more medically-intensive services, difficulties in accessing services also increased. Eighty percent of the Institute for Health and Aging organizational respondents indicated that after 1984, their agencies were inaccessible for persons with one or more of the following conditions: particular health or medical needs; mental health, mental retardation, or behavioral problems; in need of medical technological support services; with reimbursement or payment-related difficulties; requiring social supports; and not meeting agency eligibility (Estes, Swan, and Associates).[20] In home health agencies, reimbursement issues and high cost of care prevented 53% of the agencies from

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[19] New services related to complex medical care included oxygen, ventilators, IV feedings, and the need for special medical equipment. See Estes, Swan, and Associates (1993) for a detailed accounting in the increase of technology-rich services in home and nursing care settings.

[20] These categories were not mutually exclusive and all categories of persons were not barred from all agencies; the difficulty of course, was is finding an appropriate match between a frail elder, services needed, and accessible agencies.

providing care.[21] Nursing homes also faced specific access problems. They were unable to admit patients with mental health needs or behavioral problems due to changes in Medicare. Almost two-thirds of hospice directors indicated that clients without informal care-givers could not be admitted to hospice care. Higher Medicare reimbursement rates for nursing home beds also created access difficulties for those relying on Medicaid. Because nursing homes preferred to fill beds with Medicare patients, given the higher rate of reimbursement and quicker discharge, Medicaid beds became less available.[22]

The responses of community-based long term care providers to the policy changes of the early 1980s was to reorganize and eventually enter into the competitive delivery of long term care services that emphasized medical care over

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[21] For-profit agencies were more likely than nonprofit agencies to refuse services to some kinds of clients. Such refusal was not overt, but covert, occurring through such tactics as locating services in areas difficult for poor people to reach, choosing to not provide certain services often requested by poor people, and not offering a sliding-fee scale (Marmor, Schlesinger, and Smithey, 1987). These instances of difficulty in accessing services cannot, of course, be attributed only to the PPS. Discrimination (Ambrogi, Doctor, and Swan, 1988), as well as other factors, were part of the larger context and are discussed later.

[22] Medicaid beds were artificially restricted through several mechanisms. State certificate-of-need requirements, state-imposed moratoria limiting the growth of nursing home beds for Medicaid patients, and the keeping of separate waiting lists for Medicaid and Medicare patients for admission (with more openings for Medicare than Medicaid patients) were common ways of limiting the number of nursing home beds for Medicaid patients (Ambrogi, Doctor, and Swan, 1988; Kelman and Thomas, 1990; Scanlon, 1980; Swan and Harrington, 1990). Following the PPS, twenty-one percent of nursing homes reported decreases in the number of low-income patients seeking services; no change was reported for home health agencies and senior centers; adult day centers and hospices were more likely to report increases in the number of low-income people served (Estes, Swan, and Associates, 1993). Again, such practices cannot be attributed solely to the PPS, but were a result of complex interactions between the PPS, other policy regulations such as Medicare and Medicaid, and marginalization of people who were poor.

social support. In doing so, long term care was transformed in a number of important ways. It is important to note that these changes in long-term care followed the funding sources of pertinent policies; such changes were not driven first and foremost by careful attention of policy makers caring about the needs of frail elders.

First, in response to changes in policy and their respective funding streams, reliance upon market forces and competition to contain the escalating costs of care resulted in organizational restructuring of long term care agencies. For-profit health care centers, made possible by tax incentives and competitive bidding practices, became most pronounced in the home health and nursing care industry.[23] As noted earlier, this resulted in the rapid growth of proprietary interests in long term care. Concurrent with increased tax incentives and competitive bidding practices was a decline in historically provided public funds for provision of community-based medical and non-medical services, especially to low-income elders. Home health agencies shifted to private funding sources (such as private pay and insurance) rather than public funding mechanisms to fund their work, and, in doing so, shifted to using market criteria to distribute services. Szasz (1990) notes "[a]gencies reorganized and created subsidiaries; they entered into joint ventures with other agencies and other providers; they acquired or merged with other agencies" (p. 8). In short, they perceived of themselves as an industry. In doing so, the institutionalization of long term care as a market-driven industry was furthered (Estes, Swan, and Associates, 1993).

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[23] The privatization of home care, for instance, is noted by the growth of proprietary agencies during the 1980s, capturing 33 percent of the Medicare-certified home health care market in 1986, compared to only 4 percent in 1976.

Long term care organizational restructuring was also apparent in the increasing complexity of organizations' structures. This increasing complexity of organizational structure was apparent in terms of horizontal integration, vertical integration, isomorphism, and fragmentation. Regional or national chains (both nonprofit and for-profit) that transcended a local free standing community agency reflected horizontal integration. Vertical integration occurred as multiple levels of care were merged into one parent organization; affiliated business ventures, such as control of medical equipment or pharmaceutical suppliers, often became part of this integration. It was hoped that by being able to offer different levels of care, reimbursement schedules might be maximized by passing patients through appropriate Medicare and Medicaid care options (Estes, Swan, and Associates, 1993). Isomorphism, a "process of homogenization" (DiMaggio and Powell, 1983, p. 149) was apparent as for-profit and nonprofit agencies increasingly resembled each other in terms of structure, services, and accessibility to clients. Such homogenization occurred because of regulatory policy changes that encouraged similar environmental conditions for service delivery. Fragmentation was evident in both funding sources and service delivery. Multiple funding sources included local, state, and federal levels of government and numerous variations of these at the state and local level, as well as proprietary and charitable funding sources. Reimbursement strategies required the unbundling of services. These various funding streams mandated and delimited particular services in their funding of specific categorical programs, often working against comprehensive and coordinated delivery of services to the elderly (Binney, Estes, and Ingman, 1990).

A second way in which long term care was transformed during the 1980s was that it became increasingly medicalized. Medicalization is the "process by which services for the elderly are increasingly brought under the domain and rationality of biomedicine, and elements of the community delivery system are increasingly drawn toward the provision of medically related, medically supportive, and/or medically oriented services" (Binney, Estes, and Ingham, 1990, p. 762).[24] Illustrative of this, in 1986, 79 percent of home health agencies added new services classified as "high" or "medium" in terms of medical need; by 1987 this had increased to 85 percent. Also, more intensive and medically technical services, such as intravenous therapy, ventilation therapy, and enteral and parenteral nutrition therapies, were delivered at home. While the expansion of medical technology allowed for the provision of care at home at lower financial costs, rather than in institutions, it also increased demands for and demands on informal care-givers, effectively transferring millions of hours of carework to lay providers (Estes, Swan, and Associates, 1993). Also, the prioritizing of medical needs in community-based care through funding and reimbursement mechanisms accorded "legitimacy to the acute care needs while denying the legitimacy of social supportive needs of the elderly (Wood and Estes, 1988, p. 36).

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[24] Medicalization of long term care can also be understood in other ways, not in conflict with Binney et. al (1990). As a macrolevel perspective, medicalization recognizes that we construct our selves, often times, with a pervasive medical definition. How lives are interpreted and regulated from conception until death is conceptualized through the lens of a biomedical model of pathology, disease, and declining bodies. Not only does this concept regulate various aspects of the life cycle, it also redefines social problems previously understood in non-medical terms as being medical problems (Foucault, 1975). Medicalization can also refer to our fixations with high levels of technology to extend life without regard for cost (Fuchs, 1990; Illich, 1976).

Third, implied earlier, changing policies and their respective funding streams during the 1980s resulted in the process of informalization of care, that is, "the transfer of labor functions from the formal sector to the informal sector, or the shift of labor from persons working within the paid labor force to those working outside it" (Estes, Swan, and Associates, 1993, p. 13). Federal funding cuts in the 1980s along with the success of the PPS in reducing length hospital stay greatly heightened the prevalence of unpaid, informal carework outside of acute-care settings. Such care, however, was not marginal or residual but essential to the success of PPSs; it was "connected by myriad strands to the [formal] economy proper, recycling its products, provisioning its workers, supplying elements of its production process and reproducing its labor force" (Redclift and Mingione, 1985, p. 2). Care, often consisting of high-tech and complex medical treatments, once provided by paid professionals in acute care settings was now transferred to the home and provided by lay care givers. Because so much of the work that needed to occur was medically technical and complex, de-skilling was necessary. Medical tasks were broken down into smaller steps such that paraprofessionals in home health care agencies and lay careworkers in the home were able to complete such tasks. These tasks, previously performed in the hospital under close supervision, and at times performed only by physicians, were performed in the home without adequate supervision, and without legitmating credentials, thereby preventing low-paid or unpaid careworkers from capitalizing on successfully meeting such tasks. [25]

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[25] See Estes, Swan, and Associates (1993), Chapter 9 for a thorough review of the literature that addressed the issue of informalization of care in the late 1980s, specifically in the wake of the implementation of the PPS.

Finally, policy changes shaping long term care in the 1980s affected labor markets in terms of the number and type of jobs available as well as the way in which work was organized in labor market (Estes, Swan, and Associates, 1993; Estes, Wood, 1988; Szasz, 1990). Work loads were intensified to increase productivity. Nonprofit agencies adopted similar organizational and management structures to those of the for-profit sector. Federal funding for home health care jobs created new, low-skilled jobs disproportionately filled by women, and increasingly, minority women. While some long term care positions were identified as professional positions, many others were classified as semi-skilled or unskilled.[26] Significant wage differentials existed between the professional workers, semi-skilled workers, and unskilled workers, with unskilled positions being filled primarily by women of color. While the job market for these positions in the 1980s was robust, the semi-skilled and unskilled positions were characterized by low wages, part –time status, lack of or low benefit packages, and were often contractual positions to better follow the ebb and flow of patient flux.

Although a large generalization, the remainder of the 1980s in terms of public policy in long term care was a response to the PPS and DRG initiatives. In 1986, the Health Care Financing Administration (HCFA) and its fiscal intermediaries were implicated in a home health claims denial crisis. These denials resulted in an investigation initiated by the Health and Human Services Commission. The 1986

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[26] Professional positions included positions such as physical, occupational, and speech therapists, registered nurses and social workers. Semi-skilled positions included home health aids; unskilled positions included homemaker and chores workers.

court ruling in *Fox v. Bowen*, effective in 1988, resulted in revised guidelines for the Skilled Nursing Facilities (SNF) benefit. Fiscal intermediaries were forbidden to use the widely prevailing "rules of thumb" practice to make coverage determinations. Furthermore, they were not permitted to deny any physician-ordered care without providing specific clinical evidence as to why a particular service should not be covered. The 1988 ruling in *Duggan v. Bowen* resulted in revised guidelines for the home health care benefit, effective in 1989, which included qualifying patients for skilled observation (and therefore for the home health benefit) with stable health needs, liberalized homebound to include individuals who occasionally left the home, and dropped the previous requirement of expectations of improvement, thus allowing for services simply to maintain function. Predictably, HCFA denial rates dropped for both SNF and home health care types of claims following implementation of the new guidelines. Also, predictably, these liberalizations of Medicare policy enormously expanded post-acute care enrollees and expenditures in nursing home care and home health care eligibility and coverage (Prospective Payment Assessment Commission, 1997). A series of OBRA regulations from 1986 through 1990 also redefined Medicare's benefits by focusing on discharge planning rights (1986), quality of care issues in skilled nursing facilities and home care (1987), establishing new payment systems for physicians based on a relative value scale (RVS) (1989), increasing the Medicare payroll tax of 1.45 percent on income from a maximum level of $51,300 to $125,000 (1990), and beginning a number of deficit reduction plans to reduce Medicare outlays (1990) (Estes, Swan, and Associates, 1993).

Interestingly, in spite of a decade focused on polices designed to reduce federal and increase local responsibility for long term care provision and implement cost-containment initiative, federal expenditures for medical services under Medicaid and Medicaid increased, unfortunately without increasing access to health care for many. The state of long term care at the end of the 1980s was perhaps best captured by Minnesota's Senator Dave Durenberger: "[The] American health care system . . . [is] a paradox of plenty and of want, a system where some receive the benefit of the most advanced medical technologies in the world, yet many . . . families can't get help to keep a frail parent from having to go into a nursing home" (Pepper Commission, 1990).

The 1990s: The continued effects of the PPS of the 1980s were evident in the 1990s. Expenditures for Medicare's post-acute care benefits increased from about $2.5 billion in 1986, 3 percent of all Medicare expenditures, to more than $30 billion in 1996, 15 percent of all Medicare expenditures (Liu, Gage, Harvell, Stevenson, and Brennan, 1993). During the same period, Medicare spending for inpatient hospital care declined from 61 percent to 49 percent.[27]

Skilled Nursing Facilities (SNF) and home health care accounted for most of the Medicare post-acute care spending (and therefore much of its spending growth) during the 1990s. SNF spending growth was due primarily to increases in the

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[27] In fact, until recently, Medicare payments for all types of post-acute care had been growing at 25 - 35 percent a year, depending on type of provider and exact time period covered. Payments are now declining but are still substantially higher than the roughly 8 percent annual growth that characterizes other parts of the Medicare program.

numbers of users and increased use of ancillary services.[28] Medicare payments for SNF increased from $2.5 billion to $11.7 billion between 1990 and 1996 (Prospective Payment Assessment Commission, 1997). Home health care growth was furthered by increasing numbers of users and increased number of visits per user.[29] Home health payments increased from $3.9 billion to over $18.3 billion from 1990 to 1996 (Prospective Payment Assessment Commission, 1997). Increases in the number of Medicare providers accompanied increased numbers of users and services in both SNF and home health care.[30, 31]

In response to increased Medicare expenditures, as well as concerns about the projected depletion of the Medicare Hospital Insurance (HI) trust fund (Part A of

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[28] Between 1990 and 1996 the number of persons using SNF nearly doubled from 630,000 to 1.1 million persons and the total number of days covered increased from 25.1 million to 40.2 million. Growth in SNF payments also occurred because of increased ancillary services (such as various therapies) covered by Part A of Medicare (Prospective Payment Assessment Commission, 1997).

[29] Here also the number of home health care users nearly doubled between 1990 and 1996, increasing from 1.9 million to 3.7 million persons. The number of visits per user more than doubled, increasing from 36 to 77 visits per year (ProPac, 1997).

[30] The number of SNFs increased from 10,500 to 15, 5000; home health agencies from 5,800 to 9,900; rehabilitation hospitals from 813 to 1,048; and the number of long term care hospitals from 90 to 185 (Liu, Gage, Harvell, Stevenson, and Brennan, 1999).

[31] Medicaid expenditures also increased sharply during the early 1990s. From 1988 to 1995, vendor payments increased from about $49 billion to $120 billion, an increase of 13.8 percent, although the increases here were not primarily related to long-term care expenses (the percentage of nursing home expenditures, for instance, remained steady from 1990 to 1996). This increase was related to sharp increases in the cost of providing services to beneficiaries, federal legislation that expanded Medicaid eligibility for low-income families, and children, as well as increases in the number, health status and longevity of beneficiaries. From 1995 to 1996, the annual growth rate dropped sharply to just 1.3 percent, reflecting decreases in federal spending due to program caps enacted by Congress in 1993 and slow-downs in state-initiated expansions (HCFA, 1998).

Medicare), Congress enacted the Balanced Budget Act of 1997 (BBA).[32] Among other things,[33] the BBA mandated prospective payment systems for skilled nursing facilities, home health care, and rehabilitation facilities, and required a legislative proposal on a prospective payment system for long-term care hospitals by October 1999.[34] By implementing the PPS, along with reductions in provider payments in the traditional fee-for-service program, the BBA hoped to slow the rate of growth in spending for the Medicare program by approximately $116 billion over a five year period and close to $400 billion over a ten year period.[35] Overall, the changes resulting from the BBA was predicted to slow the annual per capita rate of growth on spending from a projected 6.9 percent over ten years to less than 5 percent. It is projected that this decline will slow health care spending, extending the life of the HI trust fund from 2001 to 2007 (Moon, 1999).[36, 37]

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[32] A copy of the BBA can be accessed at www.hcfa.gov/regs/budget97.htm

[33] Other components of the BBA include the Medicare + Choice (Medicare Part C) program that allows beneficiaries to choose from three types of plans (Coordinated care plans, private fee-for-service plans, and medical savings accounts) as an alternative to the traditional fee-for service; changes in office-based physician practices that, among other things, provides higher rates of reimbursement for primary care physicians, removes restrictions on settings for nurse practitioners and physician assistants, expands payment for preventive services, and reimburses services delivered via telecommunications in areas where there are physician shortages; provisions for dealing with graduate medical education; and fraud and abuse. Ettinger's description of the act as a "hodgepodge of provisions" is an apt description (Ettinger, 1997, p. 530).

[34] Except for home health care, these PPS are based on per diem payments, not per episode payments as was the case with the PPS for acute care hospitals in the 1980s.

[35] Major spending reductions come in reduced payments to hospitals ($40 billion), managed care ($22 billion), home health care ($16 billion), skilled nursing services ($10 billion), and physician payments (5 billion) (Ettinger, 1998).

[36] In terms of SNF, the BBA moved SNF into a per diem, prospective payment system that covers routine, ancillary, and capital costs, including most items and services that Medicare Part B previously reimbursed. Reimbursement rates are derived from a casemix-adjusted Federal rate and a facility-specific rate based on the

The cumulative effects of the 1997 BBA upon long term care are unknown because not all changes have been implemented. Some of the immediate effects, however, are clear. In 1998, public spending on health care, for the first time in ten years, was less than private spending on health care. The most important factor in decreased public spending was Medicare, and this decrease in Medicare was attributed to the early impact of the BBA and continued attention to rooting out fraud and abuse (Levit, et al., 2000). Home health spending of $29.3 billion in 1998 decreased from previous years by four percent and Medicare spending for home health care delivered by freestanding agencies fell nearly 13 percent. The number of new enrollees in fee-for-service home health services decreased, and the average number of visits per enrollee declined. These declines are attributed to the Interim Payment System of the BBA and continued efforts to reduce fraud. Declines in

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facility's historical costs. The Federal rate will be weighted more heavily each year during the phase-in period, and by the fourth year of the phase-in period, will be used exclusively. The PPS system for SNFs is based on RUG-III, a 44-group classification system for Medicare and Medicaid nursing home patients (Fries, Schneider, Foley, Gavazzi, Burke, and Cornelius, 1994). Using information from the Minimum Data Set (MDS), patients are classified into homogeneous groups according to health and functional characteristics and the amount and type of resources they use.

[37] For home health care, the BBA also mandated a per diem, PPS initially targeted for phase-in in October 1999 but now postponed to 2001. An interim payment system (IPS) was mandated to capture Medicare savings until the implementation of the PPS. The IPS modified Medicare' home health payment in two ways. First, it reduced the national cost limits for each type of service (from 112 percent to 105 percent of the median cost per visit) and second, it added a new criterion of an average per beneficiary expenditure limit to the payment formula. Furthermore, agency costs in 1994 were used to determine expenditure limits; this extreme formula resulted in some 750 home health agencies being forced to close under the IPS. Casemix measurement systems are less developed in home health care than in SNFs using RUG-III. HCFA is currently sponsoring several demonstration projects that are working to develop and test casemix measurement systems; other efforts, not sponsored by HCFA, are underway to create a Minimum Data Set for home care (Liu, Gage, Harvell, Stevenson, and Brennan, 1999).

nursing home care spending as a result of the BBS are not as well known. Growth in spending has slowed, resulting from slower growth of medical price increases and the increased use of non-institutional settings.

In summary, the outcomes of two influential public policies, the PPS and BBA of 1997, demonstrate the influence of public policy and its funding streams upon long-term care. The debate around these two policies, as were discussions leading to the implementation of Medicare and Medicaid, has been a discourse primarily about the economics of providing long-term care. Certainly the needs of a frail elderly population were met at some level; health care is, after all, a valued social good, and beyond health care, many states did develop and fund non-medically oriented programs for frail elders. At the level of federal policy, however, long-term care was constructed to be medically oriented, pre-empting other legitimate social and personal needs, driven by and responsive to a vendor system between providers and the state, and cost-conscious.[38] While the economics of long-term care is not irrelevant, it is not the starting point for long-term care from a public ethic of care. The starting point for caring about a frail elderly population is grounded in attentive discernment of their needs as they articulate them.

Caring For and Assuming responsibility

The second phase of care identified by Fisher and Tronto (1990) is the phase of "taking care of" or "caring for."[39] Here, someone or some group assumes responsibility for the need that has been identified and determines how best to

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[38] Trattner (1999) argues that those who benefited most from Medicaid and Medicare were doctors, pharmacists, nursing home operators and other health professionals.

respond to it. Mere acknowledgment that a need exists will not do the work of care. Resources of time, money, and skill are needed to organize and implement a caring response.

Caring for involves notions of agency and responsibility in the caring process. If someone or some group believes that a problem exists about which something can be done, then one begins to think about and respond to needs. Subsequently, the "taking care of" phase of care makes responsibility into a central moral category. As discussed in chapter three, Tronto (1994) understands responsibility not as formal obligations to which autonomous people freely commit within a larger context of distributive models of justice; rather she works with responsibility as embedded in cultural practices and political processes, and addresses questions about the responsibilities that we owe each other and society. Unfortunately, Tronto (1994) does not develop these contrasts in detail. Consequently, it is important here to expand on the notion of responsibility as formal obligations, and later, the contrast between these two notions in evaluating long-term care.

The idea of responsibility as formal obligations to which autonomous people freely commit holds forth two depictions, one of persons, and one of the goods to be distributed.[40] Persons, as depicted in models of distributive justice undergirded by dominant liberal philosophical understandings of human nature, are viewed "as primarily possessors and consumers of goods" (Young, 1990, p. 15). Hilde Nelson

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[39] Tronto uses these phrases interchangeably in her later writings. See, for instance, Tronto (1998).

[40] In this section, I draw from Hilde Nelson's unpublished paper, *Pictures of persons and the good of hospice care*, presented at the Brown Bag Series, Center for Ethics and Humanities in the Life Sciences, October 11, 2000.

summarizes the picture of moral agents under distributive models of justice in this way:

> The moral agent on this paradigm is as an economic agent who makes rational choices, based on his own assessment of what is in his self-interest, about which goods to acquire and which to forgo. He enters freely into contracts, acts under his own direction rather than being governed by social expectations or pressures, enjoys independence from external guidance, is unencumbered by ties to dependent others, and is self-assertive. In short, both as a description and as a normative ideal, the moral agent on the distributive model takes on the features ascribed to him by liberal individualism (p. 1, 2000).

Margaret Walker suggests that this picture of moral agents presents a view of individual lives as career selves (1998, 1999). A career self sets out to construct a life plan that allows one to be as economically and socially productive as possible. This understanding of career selves has been adopted by disparate contemporary philosophers. John Rawls' notion of a person is a human life lived according to a rational life plan. Bernard Williams suggests that "constitutive projects" give our lives meaning and allow us to persevere. Alasdair MacIntyre and Charles Taylor conceive of persons' lives as narratives of quests for the good; this quest gives life meaning.[41] Failure to sustain a meaningful quest narrative suggests that one has failed as a person. The difficulty with this picture of career selves, says Walker, is that it represents as normative what has been an option only for someone occupying a

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[41] See Chapter Seven of Walker (1998) for development of these philosopher's ideas.

position of privilege in a specific institutional and economic environment.[42] A career self has never been an option for those who are chronically ill, disabled, poor, and/or the object of domination. Nor has it been intended for women, whose task has been to perform caretaking responsibilities that enabled men to become career selves.

The picture of the goods to be distributed in distributive models of justice tend to suggest that such goods are primarily commodities that can be parceled out fairly and equitably, according to some set of principles. Nelson (2000), however, drawing from Young's work (1990), argues that not all issues can be accommodated by distributive theories. In particular, decision-making procedures and structures, the division of labor, and culture are nondistributive issues that determine distributive patterns. Decision-making patterns, for instance, that leave out of deliberations those affected by the decisions, can take the form of domination and oppression (Young, 2000). The division of labor as a nondistributive issue refers to how care-giving should be defined in terms of who does it, who sets the work agenda, and who executes it.[43] Culture, the "symbols, images, meanings, habitual comportments, stories, and so on through which people express their experience and communicate with one another" shapes distributive justice when, for instance, a dominant group universalizes its cultures and sets it as normative for everyone, judging those who fail

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[42] Even here, according to Walker (1998), it is not an accurate construction of such a person's life as it leaves out those times when one was not yet able or no longer able to pursue goods and projects that imbue meaning, and it leaves out the responsibilities such a person has to others.

[43] Division of labor also has a distributive aspect to it as well in terms of deciding how the work of care should be divided between various players.

to conform not only as different but as defective (Young, 1990, p. 23).[44] When decision-making procedures and structures, division of labor, and culture are cut out of distributive formulas, distributive theories of justice cannot serve as reliable guides. Nelson (2000) also argues that not all goods to be distributed are fungible. Goods of relationship can only be offered by those with whom one has shared part of one's life: "they are the goods of shared grief at the ebbing away of life, of connection to cherished others, of recognition on the part of those who matter that one's life was not lived in vain" (p. 4 – 5). Such goods cannot be commodified given that they emerge from interpersonal relations and social processes.

Nelson's (2000) assessment of the limitations of models of distributive justice is useful to evaluating long-term care. Frail elders, in need of long-term care, like Nelson's dying persons, do not fit the picture of autonomous people who freely commit to obligations based on rational choice. The notion of a career self as a self who is socially and economically productive, if it fits for anyone, certainly is not an apt metaphor for someone nearing the end of life and dependent on others in very concrete ways for survival. Neither is the notion of a career self necessarily fitting for those who do the work of care. As discussed in more detail later, decisions to care are not grounded in social and economic interests, but emerge out of complex and often conflicting motives. And in terms of the goods to be distributed, some long-

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[44] Nelson (2000) offers as an example of the injustice of cultural imperialism the possible attitudes of someone who believes passionately in the benefits of hospice care for dying persons and who, in their passion, moralize the norms of this kind of care, seeing it as the care that all reasonable people should choose. Unjust burdens and harsh judgment, then, might come to someone who opts for intensive acute care at the end-of-life, or to families who for good reason refuse to provide care at home to dying family members.

term care commodities, such as nursing home beds and services and therapies delivered by home health care workers, are clearly issues of distributive justice. They are, however, mediated by social structures, and embedded in a web of family, social, and institutional practices, practices that are invisible in justice-based conceptions of long-term care.

Nevertheless, these justice-based conceptions of long-term care are what shape and frame long-term care today. The brief historical review of the development of long-term care presented earlier gives evidence of constructing those who give and receive care in ways consistent with views of persons as autonomous, independent agents capable of making and acting on life plans. Also, attention to the goods to be distributed tends to focus most on material goods and services that can be bought and purchased; what is missing are goods of relationships as well as attention to the nondistributive issues identified by Young (1990). A few examples highlight this.

The discussion of who should care for frail elders in the United States reflects a larger social welfare historical discussion of who should care for persons unable to care for themselves. Such a discussion reflects the broader values of American society, and as social welfare historians have compellingly argued, the United States is and has been a "reluctant" welfare state (Jansson, 1997). Historically, the family, the State, and the market have been responsible to care for frail elders, although not with enthusiasm. These responsibilities have been constructed more as obligations than as sets of practices. Colonial practices of home care for frail elders, for instance, were grounded in the Elizabethan Poor Laws which legally required family support of the helpless as the first line of aid in times of need (Trattner, 1999). When the family was unable to help, ambivalent and parsimonious government help was forthcoming through means of the poorhouse. By the 1900s, with the siphoning of other poorhouse groups to more specialized institutions, poorhouses had been transformed into old age homes. The elderly needing such care were seen as social problems and understood to be in need because they were "simply a mass of bad habits" (Reinardy, 1987). Such attitudes reflected larger social perceptions of poverty as an individual problem, the logical outcome of slothful, immoral lifestyles; after all, the argument might proceed, independent, autonomous, career selves would have no need for poorhouses.

The Depression of the 1930s challenged prevailing notions of the causes of poverty as many hard-working, thrifty, and moral people found themselves facing dire circumstances. A more charitable understanding of poverty- -as something caused by social, economic, and political factors often beyond the control of individuals- -emerged as these "worthy poor" struggled to meet sustenance needs for themselves and their families. The 1935 Social Security Act contained two financial programs for the older people: Social Security (then called Old Age and Survivors Insurance) and Aid for the Aged with its Old Age Assistance (OAA) program. Social Security was understood to be an insurance program with benefits based upon contributions of an individual to the Social Security system via payroll taxes. Aid for the Aged was a state-administered welfare program financed by a categorical grant-in-aid to states, where benefits were distributed based upon need. Neither program, however, intended to assume responsibility for frail elders; instead it was thought that by providing economic security, elders would be able to care for themselves

(Benjamin, 1993; Trattner, 1999).[45] Selves, in short, were understood to be economic agents, capable of making rational choices in accordance with fulfilling individual life plans.

Even though the Depression of the 1930s was the first time the federal government assumed such large and major public responsibility for older adults,[46] a strong statement was made by the federal government about what types of citizens it believed it was obligated to support. Under Social Security, citizens were wage-earners and benefits were tied to employment. Franklin Roosevelt's agenda reflected a conservative social insurance ideology, insisting that workers should contribute to their insurance, and that their insurance should reflect wages (Katz, 1986). As such, it was a system that valued and rewarded strong attachments to paid labor, penalized weak attachments, and reflected tremendous ambivalence about providing adequate benefits to all persons regardless of monetary contributions. William Cohen, a shaper of public policy from the New Deal through the Great Society, neatly but unintentionally summed the ambiguities undergirding social security programs: "We need a system which creates no invidious distinctions based on income - - one where an individual is entitled to receive benefits on the basis of his general contribution to society" (Margolis, 1990, p. 23). The self-made, socially and economically

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[45] As noted earlier, however, the Old Age Assistance program did offer cash assistance to the elderly poor to help them live as independently as possible and purchase needed services; de facto this provision furthered the growth of board-and-care homes and proprietary homes for the frail elderly.

[46] The New Deal Era is not the first time the federal government intervened in offering public assistance, but social welfare historians generally agree that this is the first time the federal government intervened in such a major way. See Skocpol (1992) for an analysis of policy developments between 1870 and 1920.

productive career self would thoughtfully plan for retirement. In return, the State's responsibility to citizens was understood in the more formal sense of obligation; citizens as workers were owed some sort of security as they moved into later life. In equating contributions to society with contributions to the social security trust fund, Cohen overlooked the significant contributions of volunteer workers, unpaid homemakers, and informal care-givers, workers who, according to Walker's (1998) depiction, were never encouraged or allowed to develop career selves.

While the federal government recognized an obligation to care for citizens as wage-earners, it could not bring itself to extend the same level of benefits to those who were unable to participate in the formal labor market. Hence the establishment of the separate Old Age Assistance program. Katz notes that "by pointedly distinguishing social security from relief, they [architects of the 1935 Social Security Act] froze the distinction between social insurance and public assistance into federal policy, where it has been stuck over since, and built a regressive system that reinforced economic inequalities" (1986, p. 234). Patterson contends that "the most obvious characteristic [of the social security system emerging from the New Deal] was its primary reliance on contributory social insurance and its concomitant distaste for welfare" (Patterson, 1981, p. 76). While the federal government was willing to assume some responsibility in caring for those who "pulled their own weight" during their adult years, it was far more ambivalent about caring for those who did not contribute formally to the market. The federal government was willing to acknowledge limited economic dependency as part of old age; they were unwilling to acknowledge those people whose needs for assistance throughout their lives precluded them from attaining the status of citizen via their wage-earning capacities. In short, public policy regarding long-term care, scanty as it has been, has worked from the notion that benefits are provided to assist "career selves" as they bring to a close their economic and socially productive lives.

Public policy related to long-term care has rendered largely invisible those who spend their lives caring for wage-earners (so that wage-earners could be productive), and those who spend their lives informally caring for those with temporary or permanent dependency needs. As it was in Colonial Days, and up through the present, the family is the foundational centerpiece for the provision of long – term care in the United States. For women in particular, care-giving has been a normative experience. As noted earlier, about 80 percent of long-term care is delivered through home and community-based services, and while formal services are integral to this, such care cannot be delivered in the absence of an informal care-giver. A recent national survey, for example, reported that older adults with functional impairments reported using predominately informal sources of care, with less than 15 percent using formal home care (Norgard and Rodgers, 1997).

Family members perform multiple and demanding tasks in caring for frail elders. In terms of responsibility and caring for frail elders, family members perform much of the hands-on work at great economic cost. Because informal care-giving lies outside the market economy, and thus is socially and politically invisible, the economic value of assuming responsibility for caring for family members generally is not recognized. Arno, Levine, and Memmott (1999) estimate that the national economic value of informal care-giving in 1997 was $196 billion. This figure far surpassed national spending for home health care ($32 billion) and nursing home care ($83 billion) in 1997, and was equivalent to about 18 percent of total national health care spending of $1,092 billion.[47] Nor is it generally recognized that family members who provide care, no matter how willingly, do so because of complex and intricate relationships that connect them to each other. Generally it is not part of some grand master plan for their career selves. Rather, love, duty, guilt, and a host of other emotions, not all of which are admirable, draw family members to care-giving; additionally, lack of specific needed long-term care services in tandem with historic assignments of women to carework create care-giving situations that generally preclude the notion of an autonomous, self-determining individual. It is by default that many families do carework.

The goods of long-term care are also inadequate when framed through distributive models of justice. Missing from the final 1935 Social Security Act was attention to national health insurance.[48] The level of responsibility for the health care

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[47] Arno, Levine, and Memmott (1999) arrived at this figure by determining from national data sets the number of informal care-givers in 1997 (mid-range estimate of 25.8 million), the number of care-giving hours per week (midrange estimate of 17.9 hours per week), and a midrange wage rate of $8.18 (the average between minimim wage of $5.15 per hour and the average national rate for home health aides of $11.20 per hour). This figure applies to all informal care-giving, not just care-giving for the elderly. It is also a conservative estimate of costs, given the estimate of numbers of hours of informal care provided per week. Other studies dealing with subsets of chronically ill or disabled elders report much higher numbers of informal care-giving needed each week (70 hours per week for Alzheimer's disease patients, 58.8 hours per week for ventilator-dependent patients, and 22 hours per week for Parkinson's patients).

[48] While absent from the final legislation, the Committee on Economic Security did recommend a system of national health insurance as part of the Act. The American Medical Association (AMA) vehemently opposed this, however, and Roosevelt did not push the AMA on this point, fearing that he might lose the entire Social Security program.

of older adults assumed by the federal government (and to a lesser extent, state governments) increased with the passing of Medicare and Medicaid in 1965. As discussed earlier, however, neither enactment was intentional in its commitment to care about or for frail elders in need of long-term care; in fact, discussions surrounding the inclusion of home care benefits into Medicare and Medicaid were intentional in locking out benefits for persons with long-term care needs (Follmann, 1963). For whatever reasons- -costs, lack of willingness to acknowledge dependency or frailty as one ages, and/or attributions of dependency to individual shortcomings and lack of thoughtful planning for future needs- -the long-term care needs of frail elders were only minimally addressed. And while acute health care was a valued social good, provision for this and lack of provision for long-term care sends a peculiar message: if there is hope of returning one to the status of a productive and self-determining person, federal and state assistance is available; if continued functional decline is expected, one is on one's own to secure assistance or, if destitute, depend on stigmatized welfare programs.

Current tensions between Medicare and Medicaid and their ensuing fiscal tug of war over who should pay how much for what services further reflects distributive issues as well. Particularly with the Medicare restrictions in home care under the 1997 BBA, those states previously attempting to achieve Medicaid savings by maximizing Medicare long-term benefits will find that gains previously made to state budgets will decline as costs are shifted back to Medicaid (Merlis, 1999). The end result of this tension for frail elders is a fragmented and convoluted system of care that is increasingly difficult to understand and negotiate.

The market as an intentional player in caring for the frail elderly further frames long-term care in terms of commodities to be distributed by some conception of distributive justice. The market becomes a more intentional player in caring for the frail elderly beginning in the 1950s. During this time, the rise of the vendor system, the 1954 Medical Facilities Survey and Construction Act, and Congressional authorization of two additional loan programs for construction of nursing homes (the Small Business Administration and the Federal Housing Administration) increased the number of nursing home beds available, shaped the physical design of nursing home facilities, and brought together the state and the market in determining the level and cost of services (Hawes and Phillips, 1986). In response to rising health care costs in the early 1980s, the government responded with federal deregulation policies, decentralized authority and financial support in public health and social programs, and a new tax structure based on supply-side economic policies. These initiatives, along with the 1981 OBRA which promoted the growth of a market-based health care sector and limited federal contributions to joint state-federal programs, left many older adults without needed services while at the same time opening doors for increases in the number of proprietary providers and multifacility chain organizations.[49] Difficulties in accessing both home care and nursing home care was noted in the earlier discussion of the effects of the PPS upon the frail elderly. Those

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[49] To illustrate this growth, proprietary home care agencies grew from 471 agencies in 1982 to 1,899 agencies by 1986, a 90 percent increase in the years following the implementation of the PPS. By contrast, nonprofit agencies grew by only 21 percent. In terms of nursing homes, currently about 66 percent of nursing homes are for-profit in contrast to 8 percent owned by local, state, or federal governments and 26 percent non-profit homes (Kane, Kane, and Ladd, 1998).

elders with the ability to pay for needed services were generally able to meet needs; the near-poor or poor elderly, particularly those dependent upon Medicaid, found few resources beyond a nursing home placement to meet needs for long-term care, and even nursing home beds became difficult to secure given various mechanisms to reduce their availability.

Reliance on the market to care for frail elders in need of long-term care continues to increase. The 1997 Balanced Budget Act opened the door for further Medicare collaboration with private health maintenance and managed care organizations. Enthoven's claim in 1980 that managed competition is "the only practical solution" to health care costs in the United States is re-echoed by Scully's claim in 1995 that "only by eventually moving all seniors to privately managed systems operating under a defined federal contribution can the federal government truly restrain cost growth and drive efficiency into the system" (Marmor and Oberlander, 1998, p. 58).

Tax incentives and tax deductions present intriguing yet morally problematic mergers between the State and the market. President Clinton's 2000 State of the Union Address highlighted a $3,000 income-related, nonrefundable tax credit for severely disabled people and their families who care for them. Tax deductions, subject to itemizing deductions and if itemized, subject to a 7.5 percent disallowance of adjusted gross income, are currently offered for those who privately purchase long-term care insurance.[50] Although these proposals target different dimensions of

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[50] The purchase of private long-term care insurance is growing rapidly but it is still unusual for people to purchase it during their working years. In 1995, spending for private long-term care insurance amounted to $0.7 billion, or one percent of the total

long-term care, both use the tax code to address financing problems in long-term care. These tactics implicitly assume that responsibility for planning and providing for long-term care is a problem for which each individual should responsibly plan; individuals' efforts to provide long-term care would be supplanted, but not replaced, by federal assistance via the tax code.[51, 52]

In summary, when considering who has been responsible in caring for frail elders, models of distributive justice fall short. The picture presented of those who give and receive care does not reflect the interdependencies inherent in our

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revenue sources for long-term care. By the end of 1996, 4.96 million policies had been sold, an increase of more than 600,000 in 1996 alone. Eighty percent of policies were sold to individuals. Companies that offered such a benefit typically did not pay premiums; rather they offered access to coverage at group rates (Merlis, 1999).

[51] Using the tax code to solve financing concerns in long-term care is an approach riddled with problems. Both incentives and deductions benefit mainly middle- and upper-income taxpayers while offering little relief for lower-income taxpayers and no relief for those too poor to pay taxes. For instance, a $1,000 tax deduction to someone purchasing long-term care insurance in the 15 percent income tax bracket is worth $150 compared to $396 for someone in the 39.6 percent tax bracket (Weiner, 2000). Neither incentives nor deductions, if received, are large enough to make much of a difference in the decision-making of families caring for frail elders. Weiner (2000) comments that few people decide to place a parent in a nursing home based upon whether they receive a tax incentive; similarly, a tax deduction does little to reduce the cost of a long-term care insurance policy. Additionally, long-term care insurance is expensive. Wiener (2000) points out that a long – term care insurance policy, costing about $2,400 on average, if purchased at age 65 by someone in the 15 percent tax bracket who receives the full deductible of $360, reduces the cost of the policy to $2,040, a sum that is still far more than many elders can afford. Finally, although eligible taxpayers would receive only small benefits, the sheer number of people eligible for the President's tax credit would cost about $3 billion; the cost of the tax deduction is about $1 billion

[52] In addition to financial obligations, the responsibility that the federal government has assumed in caring for frail elders extends to regulatory functions and processes to monitor standards and quality of care in nursing homes. These are too numerous to mention here except to say that the 1987 OBRA stands as a turning point in the federal government's commitment to improving quality care in nursing home care. Shortly I shall say more about this regulatory function in the context of holders of responsibility and their distance from those who give and receive care.

understanding of self and family relationships; the picture of goods to be distributed narrowly reflect health care aimed at restoring one to full functioning or preventing further functional decline. Neither picture accounts accurately for decision-making processes and structures that affect the hands-on work of care, the division of labor that assigns carework to women, or cultural concerns, that, for instance, continue to assign care to the private sphere. Furthermore, interactions between the State and the market continue to commodify care as something that can be bought and sold, in contrast to something owed to citizens *qua* citizens.

Failing to 'Care For'

As discussed earlier in this chapter, there has been no sustained and public discussion about what long-term care should be in this country nor any consensus regarding the goals of such care. Subsequently, and following logically from the lack of attentiveness in caring about long-term care, a similar conversation about or agreement concerning who should responsibly care for frail elders and how best to understand such responsibilities has not occurred. The lines of demarcation in responsibility have not been decided through an open and public discussion, but rather through complex political and economic strategies and interactions, where the State continues to abdicate increasing responsibility for long-term care to the market. Families become the invisible default mechanism through which long-term care is delivered, serving as increasingly bigger and thinner safety nets.

This invisible way of assuming responsibility for frail elders is problematic from the perspective of an ethic of care for several reasons. First, this way of assuming responsibility is troubling because it keeps care out of sight as a central category of social analysis. Caring for frail elders is largely assigned to the family, historically the private sphere and the domain of women's work, and thus it is both devalued and properly contained by "self-made figures" who "find it difficult to admit the degree to which care has made their lives possible" and for whom such an admission "would undermine the legitimacy of the inequitable distribution of power, resources, and privilege of which they are the beneficiaries" (Tronto, 1994, p. 111). Confinement of care to the private sphere also takes an enormous psychological and physical toll on those who provide care, yet by confining the provision of responsible care to the private sphere, careworkers who buckle under their burdens are seen as being individually deficient and in need of support. The troubles they experience as care workers are understood as private troubles. Because of the devaluation of care work, care workers, care receivers, and the private sphere, it is difficult to catapult these troubles out of the private sphere into the public realm for critical scrutiny (Chambers, 2000). When care needs cannot be managed by the family, families turn to the market, an arena where some, but not all, are able to purchase the services they value most, and they turn to the State. Even while providing nearly universal health care coverage through Medicare and in spite of Medicaid's uneven distribution of resources to the elderly, the State does not recognize the interdependent need for care that most will need as they age; rather the State focuses primarily on the narrow dimension of acute care provision. As such it is generally distant from the work and receiving of care.

The distance of the State from the work and receiving of care is also problematic for an ethic of care. Logically, in order to accept responsibility for a problem, there must first be a recognition of the problem; we must first care about something and attend to those affected by the problem. As previously noted, discussions regarding long-term care have focused primarily on economic issues and not on how frail elders and their families define long-term care needs. Consequently, among other things, while huge public expenditures are made on behalf of the elderly, these are not always accurately targeted toward attentive meeting of needs. Thus we have some- -those who give and receive care- -who find that basic needs are not attended to in this expensive system, and we have others- -policy makers, those who must manage large public budgets, and some tax-payers- - who disparage the disproportionate amount of resources already directed to the elderly. Furthermore, those who make state and federal policy about caring for frail elderly are generally people of privilege in terms of economic and educational status (although they may not be fully aware of the privilege they possess) who perceive that they have effectively met their responsibilities by allocating resources (even though such resources may not be accurately targeted to expressed needs of the frail elderly). They are not, generally, the ones who do the actual work of care, nor are they generally receivers of care as disabled persons, and in fact they might not even be aware of their need for care given their relative ease in purchasing care services. This, in tandem with the absence of a public discussion about attentively caring for frail elders, suggests that those who care for the frail elderly may well be ignorant of precisely what is most needed.

Tronto (1994) describes this way of caring for "privileged irresponsibility." The ignorance of the relatively privileged keeps them from noticing the needs of others. The division between those with privilege who care for frail elderly by allocating budgets and making regulatory policy excuses them from "responding directly to the actual processes of care and the meeting of basic needs" (p. 121). In turn, care receivers who feel aggrieved by gaps in services cannot complain to care workers, as care workers have little power to affect policy and budgets, given their devalued status as care workers. When the concerns of care receivers reach the ears of those who are able to affect policy and budgets, it becomes far too easy for this latter group to construct care receivers as whining "greedy geezers."

The privileged irresponsibility of the State operates in close proximity to the market. As already noted, increasingly federal and state governments hand over their responsibilities to the market. Besdine (1998) points out that "the operation of the free market has, in many instances, resulted in substantial distance between the recipients of the capitation dollars and the providers of care" (p. 789). Financial pressures on large, publicly traded health care companies to outperform their competition and return a profit to share-holders creates huge pressures on such companies to reduce expenditures, particularly for the highest, resource-consuming groups, many of whom are the frail elderly.[53] In the absence of a central

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[53] One example of how privileged irresponsibility works is the recent example of Vencor, the second largest nursing home chain in the United States, and Vencor's attempt to terminate its Medicaid contract and evict all of its Medicaid residents. Vencor's executives explained that this was a strategy to make room for higher paying, private pay residents. Faced with fines, public outrage, and a district court injunction over patient dumping, the company abandoned its plan and publicly apologized for its intentions (and now plans to decrease its Medicaid population through attrition). Vencor executives claimed that the real "bad guy" is the government whose Medicaid reimbursement for costs is not adequate to cover the costs of what Vencor believes is proper care for the patient. This frustration is common to other providers of care who are caught between current payment levels,

government-driven health care reform, such as that proposed and rejected in the healthcare reform effort of 1993 – 1994, a free market-driven revolution in health care has emerged as 'managed care.' In terms of a frail, elderly population with chronic disease, an emerging body of evidence suggests that care outcomes are worse under managed care than in the traditional Medicare fee-for-service program.[54]

Our failure to intentionally care about the needs of a frail elderly population results in a haphazard system of long – term care in which the responsibilities of key players in caring for this population are not clearly identified or assumed. This failure to assume clear responsibility for the frail elderly contains care in the private sector, historically devalued in contrast to the public sector, where women, whose work in the private sector is historically devalued in comparison to men's public work, become the default providers. Receivers of care are constructed as "others," that is, those who are dependent and needy, and historically devalued in contrast to those who are able to meet their needs for care. When the need for assistance with care is recognized outside of the family, only acute health care needs are addressed while being inattentive to chronic care needs. The latter largely are delegated to the market, turning the meeting of our collective need for care as we age into a market commodity and economic problem, not a moral problem.

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high expectations of care, and increasingly higher rates of nursing home litigation which, in part, leads providers to evict those whose care is more costly than the reimbursables provided by their provider (Williamson, 1999). Both the federal government and the market provider believe they are responsibly providing care for a frail elderly population through large public expenditures; however, the care delivered to those in need does not measure up to care receiver standards or to the standards of formal care providers (assuming Vencor can be taken at their word).

[54] See Besdine (1998) for a review of supporting research.

The phase of caring for, rather than being grounded in formal obligations to which autonomous people freely commit within a larger context of distributive models of justice, is better served by understanding responsibility to care for as embedded in cultural practices and political processes. This discussion is taken up in Chapter Six.

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A PUBLIC ETHIC OF CARE: IMPLICATIONS FOR LONG-TERM CARE AND SOCIAL WORK PRACTICE

VOLUME II

By

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Chapter Five
Care-giving and care-receiving:
An evaluation of our current long-term care system

The empirical literature that addresses care-giving and care-receiving difficulties is extensive. Zarit's plea (1989) to declare a moratorium on stress and care-giving studies was in response to the proliferation of such studies during the 1980s; given the abundance of such research in the 1990s, his plea appears to have been ignored. The intent here is not to review this literature systematically or add to it, but to note, following Abel (1991), Henderson and Vesperi (1995), and Hooyman and Gonyea (1995), that it is incomplete.[1] Most of the research tends to focus on dimensions of care-giving that can be quantified, such as care-giver tasks and care-giver stress. Both topics are important, but not the whole story. Restricting

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[1] For a thorough review of the care-giving literature (that includes but is not limited to long-term care) through the mid-1990s, see Hooyman and Gonyea (1995). For a review of the gerontological literature since 1995, see, for instance, Chang, Noonan, and Tennstedt (1998) on the role of religious and spiritual coping influences on care-giver distress; Dilworth-Anderson, Williams, and Cooper (1999), Knight, Silverstein, et al. (2000), and Richardson and Sistler (1999) on stress and coping models for African American care-givers; Harris (1998) and Kramer and Lambert (1999) on unique stressors faced by sons as care-givers; Magai and Cohen (1998) on attachment styles and care-giver burden; Martire, Parris, and Atienza (1997) and Farkas and Hines (1997) on stress, care-giving, and employment; Noonan and Tennstedt (1997) on the contributions of meaning to care-giver well-being; Ory, Hoffman, et al. (1999) and Vetter, Krauss, et al. (1999) on comparisons between dementia and non-dementia care-givers' experiences; Ostwald, Hepburn, et al. (1999) and Clyburn, Stones et al. (2000) on reducing care-giver burden via psychosocial interventions; Penning (1998) and Piercy and Blieszner (1999) on balancing family responsibilities of adult care-givers to their parents; Pruchno, Burant, and Peters (1997) on mutuality in care-giving; Smerglia and Deimling (1997) on satisfaction with care-giving decisions for parents by adult children; Riedel, Fredman, and Langenberg (1998), Smyth and Milidonis (1999), Tennstedet, Chang, and Delgado (1998), and Yates, Tennstedt, and Chang (1999) on care-giver burden; Zarit, Stephens, et al. (1998) on the effectiveness of adult day care services in alleviating stress. All of these articles include succinct reviews of the literature in terms of their research questions.

research to preoccupation with these two areas restricts the range of policy options. A focus on tasks, for example, while important, ignores that such chores are embedded in personal relationships and held together by emotional bonds. To strip caring of these bonds and focus only on discrete chores diminishes our understanding of the practice of care. As we shall see, care "can't be 'cleaned up' into such categories without draining the relationship between carer and cared-for of the dimension we most need to confront. Caring cannot be understood objectively and abstractly, but only as a subjective experience in which we are all, for better or worse, involved" (Graham, 1983, p.27, 28).

Fisher and Tronto's (1990) conceptualization of the first two phases of an ethic of care, "caring about" and "taking care of" have already been discussed. The last two phases, "care-giving" and "care-receiving," move us into the concrete care encounter. Although it is tempting for ease of communication to discuss these as distinct phases, in practice, care-giving and care-receiving are interwoven, with care-giving actions responding directly to the expressed needs of the care receiver, and the care receiver accepting or rejecting care-giver acts as adequate. To separate these phases reinforces a notion of care as being one-sided, as something a competent person does for someone who is impaired. Tronto (1999) puts it this way:

> "Is care best understood as something that can only be done for others? To presume that the carer is an active agent and receiver a dependent continues to perpetuate, I would argue, some of the worst aspects of the /man/ moral agency model . . . we are trying to dislodge. The model of the carer as a

moral agent who has to decide what to do presumes an incapacitated dependent. Is this the best way to understand care?" (p. 117).

As noted earlier, the care-giving phase is the concrete meeting of needs by individuals and organizations; this is characteristically the physical, "hands-on" work of care, and usually requires "more continuous and dense time commitments than taking care of" (Fisher and Tronto, 1990, p. 43). The final phase of "care-receiving" involves the response of the individual, group, or thing that has received care. The responses of care-receivers provide a means whereby care-givers can assess whether needs have been accurately identified and met in a way acceptable to both care-givers and care-receivers.

The care-giving phase emphasizes the importance of competence as a moral action. To demonstrate that one cares, caring work needs to be performed competently. Competent care work requires a thorough and detailed knowledge of the everyday understandings of the practices of care, a flexible disposition to change care-giving strategies when warranted, basic resources such as time and money, and authority to exert influence over caring practices. Responsiveness is the moral aspect of caring that attaches to the phase of "care-receiving." Because care is concerned with experiences of vulnerability and inequality, responsiveness "requires that we remain alert to the possibilities for abuse that arise with vulnerability" (Tronto, 1994, p. 135). Responsiveness recognizes the vulnerability, dependency, and inequality that accompanies a need for care. Responsiveness requires that we consider the other's position as it is expressed by that person; thus, "one is engaged from the standpoint of the other, but not simply by presuming that the other is exactly like the self" (p. 136).

To the extent that care-giving and care-receiving is disconnected from the phases of caring about and caring for- -contexts in which resources, power, and authority to make decisions are usually located- -care practices are potentially disrupted because those closest to the situation cannot bring forth the desired outcomes. As such, competence and responsiveness speak not only to the technical aspects of carework but serve also as checks on those who routinely "take care of" situations without actually following through to see if the desired outcomes are achieved. Those who take care of a problem but feel no responsibility to supervise or interact with care-givers and care-receivers to assess whether competent care occurs are guilty of privileged irresponsibility (Tronto, 1994).

While deficiencies in care-giving and care-receiving are clear apart from an ethic of care, an ethic of care offers an alternative understanding of the sources of such difficulties, and in turn, points to alternative ways of conceptualizing and delivering long-term care. For competent care practices to flourish, the larger social and political context that shapes long-term care practices must value care as a critical variable in policy issues. We have lacked a strong secular tradition in which to conceptualize caring; instead our western tradition assumes the autonomous, rational man able to complete his life plan in the public square. Further, this tradition assumes that the self is prior to its activities and connections with others (Sandel, 1982). Valuing care as a critical variable implies paying attention to policies that allow for contextual care giving, recognize a social conception of self, and prioritize relationships. As already discussed, policies that shape long-term care in terms of caring about and caring for frail elders have followed from assumptions that ground distributive models of justice and assume that all players are autonomous, equal, and capable of self-sufficiency, or could be if medical needs were met. Such models revolve around ensuring that care is distributed fairly according to some set of principles that attempt to treat like cases similarly (thereby separating those who seemingly do not need care from those who do). Furthermore, these models are problematic not only for what they include but what they overlook, that is, an understanding of long-term care that is broader than acute care models of health that focus on restoration of health. These assumptions, following from Fisher and Tronto's (1990) framework, result in our lack of attentiveness in paying close attention to the needs of frails elders, emphasizing cost issues instead, and our unwillingness to grapple with issues of public responsibility for long-term care, defaulting instead to the family and the market as arenas in which such needs will be met. Both recourses are ones congruent with our western assumptions.

Defining Good Care

The goal of this chapter is to analyze how social-political conditions and institutional practices have shaped the practices of care-giving and receiving in home care and nursing care for frail elders, making it difficult for care givers and receivers to work effectively in meeting needs. Before addressing home and nursing care specifically, we begin briefly by noting how care-givers and care-receivers - - those closest to the process - - define ideal care. Unfortunately, it is difficult to determine what elder care-receivers of long-term care value as competent care because few studies have addressed this question.[2] Ethnographic and qualitative studies provide the most direct lens to uncovering what care-receivers value in the care process. Gubrium's elder informants (1995) spoke of the quality of care and quality of life in the nursing home against the narrative linkages they made with their lifelong experiences. Gubrium suggests that:

> . . . when residents are asked to tell their stories and speak of the quality of care and life in relation to lifelong experiences, quality is revealed to be diverse, linked with, and given meaning in relation to, life long experiences. One lesson of the narratives is that we need to begin to understand the qualities of care and life for nursing home residents in terms of the variable experiential contexts in which meanings are conveyed, which extend well into the past lives of their subjects (p. 36).

In terms of formal assessment systems then, we need quantifiable criteria of quality to determine minimal levels of care, but we also need to be mindful of the subjective meanings of people's lives. An inquiry into this might well uncover additional needs that go beyond quantified assessment criteria. Concerns about family and home, life-history, and self-worth and dependence, for instance, significantly mediate perceptions of the care process.[3]

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[2] This literature was reviewed in chapter one. We know, for instance, that elders value community-based homecare over institutional care; that older elders prefer care that maintains function and independence over expensive, acute care delivered in hospitals; and that institutional life makes difficult the maintaining of a sense of personal identity. These studies, however, do not yet tell us what precisely the criteria elders use to identify competent care.

[3] For example, Gubrium describes Bea Lindstrom, a 90-year old widow whose life narrative centers on the theme of vigilance and a lifelong pattern of independence linked to attitudes of fairness and respect. For Ms. Lindstrom, quality of care within a

Diamond's (1992) nursing home ethnography also captures implicitly what residents value in terms of care. They prefer to be known as persons rather than known by charts that document sickness and medical care; they value companionship in the middle of the night when unable to sleep; they desire a place to live in which they might share food or drink with a visitor, or be able to collectively mourn the death of another resident. Foner (1994) contrasts the care provided by Gloria James and Ana Rivera, both nursing assistants in a long-term care facility. Gloria James, the administration's favored nursing assistant, was an intelligent and efficient worker. Her patient rooms were clean and her following of care plans was as exacting as her charting. She was the worker left in charge when the registered nurse had to leave the floor. Yet her interactions with patients were cruel and verbally abusive. Foner reports the following scene:

> I tell you EAT," she yelled at one woman in the dayroom. "You don't want to eat, you can die for all I care." When the woman meekly complained that she could not eat because her foot hurt, Ms. James screamed, "Shut up and eat you. Eat. You think I have all day for you." And she turned to another woman, "You're such a nasty pig. You hear me, drink (p. 61).

Ana Rivera was an exact contrast to Gloria James, described by the coordinating nurse as one of the worst aides because she was slow with tasks, ignored bureaucratic rules, and the last one to complete paperwork. In practice, however, Ms. Rivera was warm, respectful, and emotionally involved with residents. Foner describes her as

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nursing home is filtered through her life narrative, and characteristics of quality care consist of respectful, kind, and efficient interactions with care-givers.

"one of the best nursing aides in the home and the one I would pick if I were a resident there" (p. 62).

A more systematic picture of what constitutes good care emerges from studies of care-givers' expertise. Deborah Stone (2000a), in her qualitative study of home care workers, found that private sphere caring (albeit in idealized fashion) remains the ideal. Good care was care that one would give to a loved one; ". . . care by strangers, care by people who do it as a job rather than as a family connection - - that kind of care is regarded as second-best" (p. 95). Stone's analysis led her to the following conclusions about how home care workers conceptualize good care. First, good care emphasized "talk versus tasks" (p. 95). Home care workers identified talking and listening as the basic structure for every kind of care-giving; even when the care receiver was unable to communicate, the care-giver's task was to find some way of reading "non-verbals," a skill that presumes a personal relationship with a care receiver and requires a high level of attentive concentration to determine what one is trying to say. Second, care-givers distinguished good care from bad by distinguishing between care that is grounded in love and affection for someone versus care that is simply technical, what Stone calls "love versus detachment" (p. 99). Third, good care emphasized "specialness versus fairness" (p. 101); people are unique and should be treated as such. Fourth, good care required "patience versus schedules" (p. 102). Care-givers recognized that trust was a prerequisite to completing many of the assigned tasks of care-giving, and they recognized that this required time. Furthermore, patience was required to discern individual needs of care receivers; it stood in opposition to standardization. Fifth, good care often blurred boundaries between family and work. Recipients of paid care work were often referred to by their care-givers as "just like my own family," telephone numbers were exchanged, and outings were sometimes arranged. Sixth, good care emphasized "relationships versus rules" (p. 106). Care-givers defined the relationship as the context in and means by which they did their work. Many believed that what their clients needed most was a relationship, the presence of another person who offered dignity to them by taking time to listen to them.

Similarly, Tarlow (1996) identified eight caring concepts that emerged from her qualitative study of care in three subsamples: families, schools, and voluntary agencies.[4] Conceptualizing caring as a process over time, Tarlow's informants (both care-givers and care-receivers) argued there must be *people present* who have *time* to do the tasks of caring, and that *talking* or some means of communicating was the primary mechanism for facilitating the process. The care-giver was one who was *sensitive* to the needs of the care-receiver, acted in that person's *best interest*, was *emotionally invested* in the relationship, and *did helpful things* for the other. Finally, the care-receiver must *respond* in such a way that indicates he/she wishes for the relationship to continue. To participants in this study, "caring meant an ongoing process of supportive, affective, and instrumental exchanges embedded in reciprocal relationships" (p. 81).

Ironically, given their closeness to care-giving situations, only a few studies have investigated the views of nursing assistants regarding what constitutes good care

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[4] Tarlow's study (1996) did not address care-giving and care-receiving specifically in terms of long-term care for frail elders.

in nursing homes. Schirm et al. (2000) found that nursing assistants emphasized caring as an inner quality learned through training and experience wherein one learned to pay close attention to what people need. These nursing assistants noted such details as paying attention to breathing, non-verbal expressions, rate of swallowing when eating and eagerness for food as subtle cues one learned on the job. These were important to pay attention to if one wanted to express care. The informants noted that their work environments affected care-giving. In particular, the experience of being short-staffed and having time for only minimal necessities, lack of team work, lack of respect from nurses who did not take perceptions of nurse aides seriously, and strict boundaries between the roles of nursing aide and nursing work (such that nurses were unwilling to assist in basic care) affected care-giving negatively

Benner and Gordon (1996) also emphasize the processural and relational notions of care practices.[5] Specific skills and practices are needed to move from concern to engagement and presence. Care practices are culturally constituted, socially embedded ways of being in a situation with others. They are located within a tradition, worked out in history and through ongoing engagement with others. As such, they can never be reduced to technical formalities or completely objectified, but "are always dialogical, existing in human interactions that demand responses. It [care] cannot be defined separately from the being in and doing of the practice" (p. 46). It is a process, suggest Benner and Gordon, similar to Heidegger's vision of a fine craftsman:

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[5] These authors' context is the nursing profession.

> [The learning of] a cabinetmaker's apprentice . . . is not mere practice, to gain facility in the use of tools. Nor does he merely gather knowledge about the customary forms of the things he is to build. If he is to become a true cabinetmaker, he makes himself answer and respond above all to the different kinds of wood and to the shapes slumbering within the wood - - to wood as it enters into man's dwelling with all the hidden riches of its essence. In fact, this relatedness to wood is what maintains the whole craft. Without that relatedness, the craft will never be anything but empty busywork, any occupation with it will be determined exclusively by business concerns. Every handicraft, all human dealings, are constantly in that danger (cited in Benner and Gordon, 1996, p. 46).

From both care-giver and care-receiver perspectives we learn , then, that the precise qualities of competent and responsive care-giving relationships are not reducible exclusively to a string of variables than can be tested empirically. Rather, what works and what does not work, what is helpful and useful in care and what is not, unfolds over time in the context of particular relationships. Such a process requires time, attentiveness, and responsiveness. As we will see, public policies that shape organizations and service delivery systems are often at odds with how care-givers and care-receivers experience good long-term care in nursing and in home and community-based settings.

Home and Community-based Care

As discussed earlier, the development of home health care has been legitimized primarily as a cost containment strategy to save on hospital and nursing home costs. As such, it is understood primarily in medical terms as a medical service. The primary controlling public policy for delivery of long-term care in the home is Medicare, a policy intended to meet the acute health care needs of persons over the age of 65.[6] Furthermore, because home health care is perceived as a cost-cutting and cost-containment strategy, it is likewise evaluated by these characteristics. These assumptions - - that home care is primarily about medical care and about cost containment - - result in several policy strategies designed to reduce and contain home care expenditures. The intrinsic value of home care to care-receivers and care-givers, because it was never part of explicit discussions concerning the needs of frail elders, is also never part of policy calculations in evaluation. Following Deborah Stone (2000b), policy strategies to increase medical, fraud, and managerial control and shifting care work to unpaid care-givers are considered; the deleterious effects of these policies on our understandings of what constitutes good care is also considered.

Medical Care: To reinforce that home care is about medical care, assorted medical control strategies attempt to limit who is eligible for services and define what services those who are eligible will receive. Patient classification and case-mix systems of the BBA of 1997, following the PPSs of the 1980s, attempt to identify individual care needs from observable patient characteristics, link them to corresponding treatments, and predict resource utilization based on these categories. Medicare-reimbursed services are limited to what is medically necessary as determined by a physician; this criterion is tightened with the 1997 BBA in requiring

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[6] While many states have developed non-medical, supportive care programs that do not require skilled medical care as a prerequisite for service, the point here is that federal policy on home care is driven by medical model assumptions.

that each patient be examined by a physician before certification as "medically needy" and insuring organizations are enforcing this more rigidly than before. Medicare policies also limit reimbursement to skilled services delivered to persons who are homebound.[7]

Apart from the questionable assumption that home care is about medical care only, on the face of it, these policy strategies related to medical care seem reasonable. Closer examination, however, yields several shortcomings. The payment systems flowing from patient classification and case-mix systems are grounded in a deep faith in medical science that individual care needs can accurately and objectively be identified and linked to treatment. Empirical evidence demonstrates, however, that these case-mix systems provide only a crude measure of patient care needs (Iezzoni, 1997); in fact, a recent HCFA-commissioned study found that the proposed payment system can account for only 32 percent of the differences among patient costs (Case-Mix Adjustment, 1999). Although this process is similar to the PPS system implemented in the 1980s, hospitals were then discharging patients to nursing homes, rehabilitation centers, or home health care, settings that became more sophisticated in their medical care to fill the gaps left by early discharges of increasingly more ill persons from hospitals, and which served as a safety net for patients whose level of need was inaccurately assessed prior to discharge. Home health care agencies have no place to discharge patients for whom they cannot afford to care; nor is there a safety net for those patients whose care turns out to be more complex than estimated.

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[7] This is summarized from the 1997 BBA, available online at www.hcfa.gov/regs/budget97.htm

The best home care agencies can do is discharge expensive patients from their program, leaving them without services, and/or arrange nursing home placements, encourage the use of hospital emergency rooms, or refer them to state-funded, non-medical, personal-care programs. Consequently, the classification and case-mix systems implemented with the 1997 BBA will continue to create new "no-care" zones for medically-needy people, forcing them to go without care or enter institutions prematurely.

The policy strategies related to Medicare's medical necessity, skilled-services, and homebound criteria are also problematic. The criteria that define each of these strategies is elastic and shifting, and not nearly so scientific and objective as policymakers would have us believe. Physicians hired by insuring bodies, for instance, often define medical need differently than physicians who see and treat patients. The latter's judgment is under careful scrutiny by third party reimbursers, and disputes are frequent (Rosenbaum, Frankford, Moore, and Borzi, 1999). What constitutes "skilled care" is also slippery. Prior to the Medicare laws becoming more expansive in 1989, skilled care included only hands-on, physical treatments; the addition of "judgmental work" of nurses was more a function of political compromises than a change in the definition of skilled care. Furthermore, as sophisticated high-technology care has moved into the home, unpaid care-givers are performing treatments that at one time, only trained health care workers were allowed to perform.[8] There is little to prevent cost-conscious policymakers from continuing to

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[8] For instance, family members are permitted and required to perform diagnostic tests, give injections, administer IV therapy, operate respirators, and perform tracheotomy care.

classify previous skilled medical care as unskilled care.[9] Under Medicare's "homebound" criterion, there is no objective way to distinguish homebound persons from non-homebound persons. Although regulations are written to sound as if such determinations can easily be made by a qualified physician, in practice, they are not clear.[10] What does it mean, for instance, that to be considered "home-bound" one must be able to leave the home only with a considerable and taxing effort? Why is it that trips to physicians' offices are not counted against patients, but trips to visit family and friends are counted against patients.

In short, cost-saving priorities, social norms, and changing political tides determine medical policy on behalf of frail elders. Those with the power to define eligibility criteria- -policymakers and politicians- -mask judgments that are a matter of social responsibility behind medical criteria and the social authority we ascribe to physicians; in practice, however, physicians and other health care workers do not have the authority one might expect to develop care plans for patients in the manner they judge best. This gap between those who set long-term care policy (those whom Tronto would say enjoy "privileged irresponsibility") and those who must live within the defined medical criteria places care-givers in difficult and compromising situations. Reclassifying skilled care as deskilled care shifts enormous burdens of

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[9] The controlling document, the Medicare Intermediary Manual that sets the legal standards by which intermediaries are to determine allowable claims, says that "where a service can be safely and effectively performed by the average nonmedical person without the direct supervision of a licensed nurse, the service cannot be regarded as a skilled service although a skilled nurse actually provides the service." (Section 3118.1, quoted from Results of the Operation Restore Trust Audit of Medicare Home Health Services in California, Illinois, New York, and Texas, 1997, Department of Health and Human Services, Office of the Inspector General, p. 8).

care to family members.[11] Interpreting vague criteria often places paid careworkers in ethical quandries in documenting their patients' progress and puts care-receivers in ambivalent frames of mind about progressing. To encourage patients to develop and participate in support systems outside of the home risks the loss of home-bound status. A patient who gains enough mobility to walk to her mailbox may be at risk of losing benefits unless such a walk is described very carefully, laboriously noting the aftereffects of pain and fatigue from such exertion. Some workers intentionally refrain from fully charting a patient's activities because they know that should they do so, the patient stands to lose eligibility. Deborah Stone (2000b) notes the perverse paradoxical nature of this requirement: "These programs are supposed to provide the care necessary for people to be able to function as social beings, but they make access to care contingent on remaining isolated inside one's home" (p. 12).

Fraud Control: Fraud control policy strategies also attempt to contain homecare costs. Fraud is monitored in Medicare and Medicaid programs through the Office of the Inspector General (OIG) within the Department of Health and Human Services. The OIG's 1995 Operation Trust, set up to investigate home health care, nursing home care, and medical equipment companies in the wake of some highly publicized cases of home health billing fraud cases, claimed to find rampant fraud among health care agencies; in fact, concluded the OIG in a highly publicized result, 40 percent of all home care cases were fraudulent (Office of the Inspector General, 1997c). A closer analysis of the report, however, indicates that while some instances

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[10] For instance, specifying the number of hours per week someone may leave the home and for how long gives the illusion of objectivity and clarity.

[11] This is discussed in more detail later.

of serious fraud were uncovered, the majority of questionable cases were ones which grounded in legitimate disagreements about how to interpret subjective and elastic criteria, such as those noted earlier, or honest clerical mistakes. Among the 1,539 unallowable services the auditors identified, more than 50 percent of the claims had to do with differences in determinations of "medically necessary" and "skilled care;" another one-third of these cases were over disagreements concerning the home bound requirement, and a final 16 percent over "valid physician orders."[12] Less than one-half percent of these claims were truly fraudulent in the sense of overt corruption (i.e., services that were never delivered). Two and one-half years later, the OIG repeated the study, and claimed that the rate of inappropriate claims had decreased from 40 percent to 19 percent (Office of the Inspector General, 1999).

The perception of rampant fraud had, however, already made its impact on the public.[13] This perception harms legitimate agencies, careworkers, and care-receivers in several ways. For above-board agencies, the audits are time-consuming, expensive, and emotionally-wearing. If errors are found, financial penalties are substantive. Even more difficult is the equating of judgment differences with fraud, and the toll this takes on the agency's standing in public. For care workers, this atmosphere of mistrust and fear filters into their work as well. Proper documentation

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[12] This category included such offenses as claims signed by assistants' in physicians' absence, care begun before an official order was submitted, etc. Such practices are common in health care where those careworkers closest to patients often observe more quickly changes in patients' status and subsequent needed services. Such changes are reported to nurses, who then inform physicians of changes and suggest what ought to be prescribed. Physicians then give verbal assent to the care plan before officially entering an order.

[13] See, for instance, Pear, 1997; Pham, 1997; King, 1999.

takes precedence over meeting patient needs, and workers worry that their errors will jeopardize their careers or the agency's existence. Furthermore, they are forced to make ethical compromises in their documentation, looking for ways to justify care for someone who needs care but does not fit the specified criteria.[14] They attempt to frame patient problems in a particular light so as to justify services, or they might code visits as services that are reimbursable even when they are not because they know the need for care is great. Some workers provide care on their own time, telling no one about it, billing no one for it, and experiencing tremendous guilt for their "subversive" care (D. Stone, 2000a). For agencies and care workers, the fear of delivering fraudulent care, or the fear of being caught doing care that one would perform for a loved family member even though it is not reimbursable "gradually undermines the precious social trust between needy citizens and people who care for a living; and by stigmatizing and penalizing the entire home care work force, it stifles the compassionate instincts of professional care-givers" (D. Stone, 2000b, p. 16).

Managerial Control: Managerial control policy strategies also attempt to contain homecare costs. In particular, home care providers are controlled through prospective payment systems such that they have a strong financial incentive to avoid patients who will need extensive services. This "skimming," hidden behind bureaucratic euphemisms of "balancing high- and low-cost patients to stay within

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[14] One of Stone's home care worker informants, for instance, described the quandaries she faced with patients who have Alzheimer's disease. While they often are mobile, thus not meeting the criterion of "homebound," they forget to eat. Consequently, the worker attempts to find other medical problems to justify continued home care (2000b).

revenue limits," leaves sicker patients to rely on families or institutional care.[15,16] Consequently, the largest share of care work falls to the family.

Medicare, in addition to a number of state-funded programs, also attempts to control informal care by withholding formal funding for home care; as such, they will cover home health aide services only "when there is no family member or support system able, available, or willing to provide these services."[17] The characteristics of able, available, or willing, are open to interpretation, but since the BBA of 1997, nurses report far less discretion in their ability to interpret this standard and more forcefulness in requiring some family member to step forward. Stone's home care worker informants speak to this: "Before, we would never force a family to learn to take care of a relative... If no one in the family wanted to learn to do it, we didn't force them. Now we say that someone has to take care of this person... We're forcing people to rely more on their families, which is a different idea in this country" (D. Stone, 2000b, p. 22). Furthermore, recent additions to Medicare's regulatory instrument, the Outcome and Assessment Information Set (OASIS), asks several pointed and detailed questions about able, available, and willing care-givers.

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[15] Such an outcome was predicted in two analyses of the Interim Payment System (Komisar and Feder, 1998, the Lewin Group, 1998). Anecdotal evidence suggests this has occurred (U.S. General Accounting Office, 1998).

[16] Nursing homes, however, are not immune from PPSs, and they also have every incentive to avoid costly, long-term care patients who need (or eventually will need) Medicaid.

[17] HCFA publication 11, section 206.2, quoted in Results of the Operation Restore Trust Audit of Medicare Home Health Services in California, Illinois, New York, and Texas, 1996 (1997), p. 8.

Stone notes that should HCFA decide to implement more rigidly its eligibility requirements, it would have the detail it needed to do so.[18]

Shifting Care to Informal Providers: Public policy for funding formal home care, then, ensures that friends and families provide as much care as possible without pay. For some, this is good public policy because it contributes, the argument goes, to shoring up modern families. Morally, families are responsible to care for their own, and public policy that grounds this responsibility is sound policy. Furthermore, this arrangement leaves in place a patriarchal family structure, and legitimizes womens' roles within it. Financially, given that resources are limited, when care can be provided "at no cost," public dollars can then be allocated elsewhere.

Valuing public policy, however, because it shifts the burden of care to unpaid family members is problematic in a number of ways. A wealth of empirical data confirms that the physical and emotional well-being of care providers is severely compromised by overwhelming responsibilities.[19] Furthermore, although many elders prefer to live in their own homes, many do not wish to be cared for by family members; concerns of being a burden, and/or awkwardness and shame about personal care being provided by a child are commonly cited reasons for not wanting family

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[18] Ironically, the OASIS asks no questions about the needs of informal care-givers. Thus its questions about informal care-givers appear to have as their outcome some basis for excluding people from care, rather than a full and robust accounting of need for additional services. Such regulatory tightening will be more detrimental to women than men, given the number of women care workers, and cultural expectations of women as care-givers. Furthermore, when men serve as care-givers, more formal resources are available to them, and these increase with length of time in the care-giving role. Conversely, women care-givers receive less allocations for services, and these decrease over time (Abel, 1991).

[19] See footnote #1 for a review of this literature. See also Abel, 1991.

care-givers (Estes, Swan, and Associates, 1993). For some frail elders, unpaid care-givers cannot meet all of their needs. Consequently, they need assistance from paid care-givers as well, but such assistance is not forthcoming when estimates of need are based upon crude measures of the presence or lack of unpaid care-givers.

Home Health Care and an Ethic of Care: Although implicit in the discussion above concerning the limitations of public policy to adequately provide long-term home care in a way that meets the ideals of care as set forth by care-givers and care-receivers, such strategies for cost containment do not comport with a public ethic of care and its emphasis upon policy that affirms a social conception of the self, is contextualized, and prioritizes relationships. Medicare's attempt to solve distributive conflicts with medical criteria is limited; human needs are imprecise, and attempts to classify such needs involve making moral judgments and considering social norms- - large issues that go well beyond supposedly objective scientific criteria.

Social conception of self: In terms of policy affirming a social conception of the self, Medicare as the controlling federal policy for home care comes up short. The intentions of the initial Medicare legislation were to provide acute care for persons over the age of 65; as such, when applied to home care, the self is defined narrowly in physical terms only.[20] The goal of care is to return someone to their previous level of good health so that they continue to function autonomously and

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[20] Although the focus of this discussion is not on the Social Security benefit for elders, this policy also constructs the self narrowly as someone who, if given sufficient economic support, can be independent and autonomous. Weinberg (1999) notes that "a survey of the non-AFDC Social Security Act and its revisions over the years suggests a statutory fiction of a beneficiary who, although elderly or disabled, is socially autonomous, needing only economic support" (p. 266).

independently. The means to autonomy and independence is through acute, often high-technology, medical care. Frailty, dependence, and disease are not part of the equation, even though this will be the experience of many.[21] In its limited scope of the self as a physical being, social care in home care is squeezed out. Time for talking and listening, the backdrop for discussion of life events and reminiscing and what Erikson calls the achievement of integrity, is devalued. Stone (2000a) notes that in the home care agency she studied, over 50 reimbursable tasks for home care workers are listed in care plans. Not one is talking or listening. Relatedly, trust as a prerequisite for being able to complete care-giving tasks is essential. This takes time and requires some kind of communication. To devalue the importance of developing trust and the time it requires suggests that care-receivers are passive recipients of medical procedures done to them, and assumes that they experience no sense of shame or fear about their need for care. What is missing from the payment systems in home care (and missing from all federal policy regulating long term care) is a system of accounting for the social aspects of care. Stone reminds us that:

> medical care, especially relatively long-term home care, is to a significant degree social Except when a patient is comatose or anesthetized, there is some kind of social interaction between care-giver and patient, and this interaction is essential to care. . . . We don't know how to codify the social ingredients of care in treatment protocols or care plans – how to preserve

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[21] Witkin (2000) reflecting broadly on cultural assumptions about aging, reminds us that the aging scenario of independence, autonomy, and freedom from disease is a picture of aging which, if it belongs to anyone, belongs to people like himself who have always had access to resources that contribute to health and longevity: "But as a

> people's dignity and identify, how to allay their fears and boost their hopes, how to foster their social bonds, how to encourage them to participate in their recovery, how to make them feel cared for and loved. The social aspects of care depend on the unique personalities of care-givers and recipients and cannot be reduced to measurable tasks. They are invariably omitted from a case-mix classification system. And medical care that treats only physical ailments, that addresses the body but not the person, is not good medical care. While health-care professionals are often very skilled at providing this kind of social care in the interstices of their more technical interactions, there is a certain – often very large – amount of variation in the time this kind of communication requires, and this variation is even less accounted for in formal classification systems (Stone, 2000b, p. 9).

Recalling that attention to a social conception of the self in policy arenas requires that we consider not only care-receivers but care-givers, and given that good care is care that does not compromise the autonomy of care-givers, it is important to consider care-givers also.[22, 23] Characteristics of unpaid care-givers have already

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white, male university professor I am a member of a privileged class for whom these aspirations are possible" (Keigher, Fortune, and Witkin, p.23).

[22] I focus here on informal or unpaid care-givers; concerns about paid care-givers will be addressed in the discussion about nursing care policy as the issues facing paid care-givers in both settings are similar.

[23] The link between autonomy and the social conception of the self is complex. Interested readers will want to consult Clement (1996) for an extended discussion of the congruence between autonomy and a social conception of the self as it relates to care-givers. While we speak the liberal language of individual rights and autonomy, we overlook the social conditions that foster such autonomy. Thus, for women care-givers, the ability to make supposedly autonomous choices about whether to provide unpaid care is constrained by few, if any, other affordable options for such care for their loved ones. Furthermore, women's inability to be make autonomous choices is

been discussed in terms of the number of hours of care they deliver, estimated economic value, and the stresses, burdens, and benefits that attach to it. The societal response to burdens of unpaid care-givers is also important to address. Historically, the understanding that someone needs to provide care has been a necessary but invisible piece of public policy.[24] Because informal carework is rendered invisible through lack of pay and lack of benefits, the magnitude of sacrifices entailed by carework is not recognized as labor; the notion of such work as being "free" or "natural" to women is reified, and the overwhelming isolation for care-givers in this private arrangement is overlooked (Weinberg, 1999). Furthermore, the assumption that carework is the responsibility of the family is reinforced. Clark suggests that this "ideology of "familism" shapes family care at the domestic level by relying on "family values" rhetoric, and at the policy level by assuming that good government is government that stays out of family life. In doing so, we maintain ". . . the illusion of the family as a private domain, presenting the traditional family as responsible for dependents and a gender-based division of labor as normal and natural; . . . the state supports and sustains the inequities of these relationships without appearing

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reinforced by their historically marginalized and intermittent work in the labor force, thus making it difficult economically for women to chose continued paid employment over the expenses incurred through hiring paid care-givers. See Abel (1991) for an extended discussion of this in the context of motherhood.

[24] It has been only in AFDC programs, and to a lesser extent in policies related to foster parents, that care-giving roles have been legitimized. With TANF, the legitimacy of the care-giving role of poor women to their children is lessened while ironically, such roles are idealized in conservative, middle-class "family values" rhetoric.

intrusive" (Hooyman and Gonyea, 1995, p. 112). One of the end results, however, is that:

> [t]he decisions women make about care are not solely private choices. Because publicly funded services are not universally accessible, many women lack the power to determine when they will begin to care for elderly parents, the power to control the intrusions of care-giving in their lives, and the power to hand over responsibilities that have become overwhelming" (Abel, 1991, p. 22).

Hence, when difficulties arise in terms of the care-giving abilities of the family, or more particularly, women, the coping capacities of women are targeted in intervention. Consequently, in the empirical literature we see numerous studies of interventions designed to support families in their care-giving roles. These generally take the form of education and training, support groups, and respite care.[25] In fact, this is an arena in which social work practitioners historically have been key players. While these intervention strategies and programs can and are useful to care-givers, it is important to look closely at the assumptions and motivations behind these programs.

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[25] For instance, Smerglia and Deimling (1997) suggest interventions to increase family decision-making skills and support of husbands for wives in care-giving roles as stress reducers; they also suggest that casemanagers think in terms of support that builds care-givers' sense of confidence and ability to cope. Otswald, Hepburn, et al (1999) report the results of a three-year randomized clinical trial testing the effectiveness of an interdisciplinary psychoeducational family group intervention in decreasing care-giver burden and depression. Clyburn, Stones, et al (2000), investigating the predictors of care-giver burden and depression, recommend educational interventions that assist care-givers manage more effectively difficult care-receiver behaviors and increase their own coping and stress management

First, many of these programs have as their goal cost-effectiveness and efficiency. From an ethic of care, these intervention programs do not begin with the needs of care-givers or include such in their evaluation. Care-giver health, financial conditions, or social and emotional concerns are absent from the intervention. Second, intervention programs are severely underfunded. Competent care-giving presumes adequate resources (Tronto, 1994). Third, attempts to measure care-giver experiences (usually stressors or relational support services) are measured simplistically so as to be captured by quantitative analyses. Social support, for instance, is often operationalized by the frequency of visitors to one's home, with no apparent awareness that for some care-givers, such visits are more burdensome than helpful. Another mechanism by which complex care-givers's experiences are measured is by focusing on physical or mental outcomes of stress, a strategy that imposes a narrow medical model on care-giving and neglects the social and economic factors that create such problems. Such an emphasis can lead, for instance, to concluding that the high rate of depression among care-givers should not be a concern because depression can be treated through therapy, medication, and support groups.[26]

Finally, and following from the above, support services and education programs respond to care-giving as a personal, not public, problem. To borrow from Mills (1959), difficulties in informal care-giving are seen as "the personal troubles of the milieu" rather than the "public issues of social structure" (p. 8). As such, interventions that focus on adapting to stress support the status quo, the traditional

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techniques. Hooyman and Gonyea (1995) provide an extensive review of the intervention literature for care-givers through 1995.

role of women as natural careproviders in the private sphere. Solutions are placed squarely on the shoulders of already-burdened care-givers to enhance their coping abilities and to find meaning in their work.

Seen as a private trouble, care is a women's issue (relatedly, seen as an economic problem, it is relegated to the market). In any event, recognizing the universal need for care at various points in our lives is not recognized as a public concern or value; the structural and ideological causes of informalization of care are ignored, thus relieving us of seeking more complex policy changes to reorganize public policy. The wrong kinds of questions are asked and answered. Instead of asking why it is that care-givers should attempt to adapt to such unfair and overwhelming private burdens, we design interventions to assist them in their compliance. We fail to ask how home care can be delivered in a way that is caring and just for care-givers and care-receivers. We fail to recognize informal care-giving as an essential human activity that shores up the social fabric of our lives, that serves as the bedrock of our nation's long-term care system, and as a valued human resource. Instead, we either romanticize it or devalue it; we fail to recognize it is a "labour of love in which the labour must continue even when the love falters (Graham, 1983, p. 16).

Contextual care practices: Policy that shapes and delivers home care also struggles with establishing policy that allows for contextual care practices. As contextual care practices, decisions that are made about how best to care would be

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[26] See Abel, 1991, for literature review of researchers who conclude that depression is not a serious concern.

grounded in the care-giving-care-receiving relationship. The knowledge about what is best for another person would arise from the actual care experience. Medicare falls short here, in part because it was never intended to address home care needs and in part because Medicare itself is shaped by societal values and moral assumptions that have kept care concerns out of the public venue.

As already noted, Medicare shapes the form of home care by constructing it as medical care designed to return someone to their former level of functioning. Often this goal is not shared or prioritized by those in the care situation, and problems arise. This is seen clearly, for instance, in situations where elders who have dementia need care. The increasing forgetfulness, memory loss, confusion, and need for assistance with ADLs puts elderly demented persons in vulnerable and potentially unsafe situations, even though physically they may be healthy. Care-givers of persons with dementia spend significantly more hours per week than care-givers of non-demented persons providing care. They report greater impacts in terms of employment complications, care-giver strain, mental and physical health problems, time for leisure and other family members, and family conflict, even when controlling for sociodemographics and level of care-giver involvement. It appears that "there is something unique about caring for a demented older adult, apart from care-giver characteristics and level of care-giving involvement, which leads dementia care-givers to experience greater strain" (Ory, Hoffman et al, 1999, p. 184). Bowman, Mukherjee, and Fortinsky (1998) speculate that this "something" are cognitive impairments, finding that such impairments were correlated with increases in all measures of strain for unpaid care-givers (i.e., global, personal resource, competing demands, and level of emotional upset). Yet because such impairments are not seen as physical or as remedial, Medicare home care benefits do not extend to this large group of elders or their care-givers unless need can be constructed as medical need.

The limitations of Medicare as a home care benefit that allows for contextual care is not limited to unpaid care-givers and care-receivers. Deborah Stone (2000a, 2000b) documents the effect of Medicare regulations on home care workers. The inability to flex the definition of medical need in tandem with cost containment constraints and fears of being singled out for fraud, on the one hand, and a deep concern for elder clients unable to receive good care, on the other hand, puts paid workers under constant moral burdens. They are unable to do enough of what they think they should do, and when they do what seems to be the morally correct thing to do, they risk reprimand or dismissal. Stone notes that most policy makers for home care have been worried about cost containment, the wood work effect, and that paid care will replace family commitments. They ought to worry instead about a different kind of displacement: "the displacement of caring relationships and social connections by narrow, task-oriented bodily maintenance; the displacement of empathy and affection by cool professionalism and calculated fiscal prudence; and the displacement of an ethic of responsibility for one's neighbors by an ethic of working-to-rule" (1999, p.67).

The rise of these latter kinds of concerns cannot be attributed solely to Medicare as the controlling policy for home care; instead such concerns emerge out of a particular societal ethos that shapes not only Medicare policy but also bureaucratic and professional norms affecting contextual care practices. Professional norms as carried out in bureaucratic institutions, for instance value fair and equal treatment for care receivers while the demands of contextual care require treating care receivers as unique and in need, sometimes, of treatment that is different from one what another might receive. Stone (2000b) comments,

> "[c]aregivers in the public world are caught in a moral double bind. They cannot give good care by their own standards if they do not love their clients, if they do not allow themselves to let strong attachments develop, and if they do not treat each client uniquely. But they cannot be good professionals, good workers, or good citizens if they violate the norms of impartiality and equal treatment that govern public life and that have been drummed into them since kindergarten civics and before. Individual care-givers are left to reconcile these conflicting moral imperatives" (p. 102).

Relatedly, good care-givers recognize that great patience is required to discern the individual needs of a care-receiver, and flexibility in one's schedule is required to respond as needed. Listening attentively and responding empathically to suffering requires expanding our emotional knowledge such that we are able to enter into the perspectives and experiences of others (Carse, 1996). Such skills and practices, however, are the opposite of standardization and strict efficiency schedules.

Contextual care practices within organizations are hampered by organizational imperatives of rationality implicit in bureaucratic structures and professionalism, argues Dill (1993). These organizational imperatives are bolstered by seemingly neutral technical, scientific, and individualistic definitions of need and service that emphasize technical system operations and technical fixes to perceived system problems of precision, speed, efficiency, and standardization. The problem with this from an ethic of care, however, is that some elements of human need are not captured by assessment instruments that develop in such a context, and some client information is lost because it does not fit with the categories of assessment. Human need, as defined by persons with needs, gets lost in this scheme; rather the political process creating the bureaucracy defines who and what it will care about, "and shapes caring to the agency's changing purposes and need for self-perpetuation" (Fisher and Tronto, 1990, p. 49). Loneliness, companionship, and assistance with ADLs outside the context of a medically defined disease, for instance, are not visible in bureaucratic constructions of or solutions to need. The results, says Dill, "are distortions and transformations of client narratives, vulnerability of systems to goal displacement, and conflicts of frontline staff in negotiating between client and organizational realities" (p. 459). Furthermore, in bureaucratic systems, as one gains status by gaining advanced knowledge and skills within a particular profession, one moves further away from the work of care-giving. The careworker at the bottom must carry out her working in line with routinized procedures developed by someone far removed from the process of care-giving and faced with conflicting demands in terms of care-giving. They must often break the rules to provide good care, and in breaking the rules, they are reprimanded. Yet they also carry cultural expectations that they will be empathetic and compassionate, because they are women, even though no time is carved out in their work for such expressions.

Prioritzing Relationships: Just as it is difficult to affirm the social conception of selves and provide care that is contextual given current arrangements, it is also difficult to prioritize relationships. Good care as defined by care-givers and care-receivers is care that is grounded in love and affection for someone versus care that is simply technical. "All care-giving," says Abel (1995), "involves emotions and relationships" (1995, p. 42). Abel's (1991) study of women care-givers found that women seldom perceive care-giving as a series of discrete chores to be accomplished. Rather, (unpaid) women care-givers emphasized responsibility and relationship themes; they spoke of the desire to foster self-respect and dignity of those for whom they cared in their care practices. Home health care workers in Stone's study (2000 b) developed intimate relationships with patients. In spite of their training and the strong professional norms against becoming too close to clients, they often came to think of their clients as friends or relatives. Karner (1998) found that home care workers, through a mutual process of affirmation with the families in which the care provided was congruent with family expectations, often became "fictive kin." This negotiation positively shaped the relationship between the care-giver and care-receiver, allowing the care-receiver to maintain the cultural ideal of family care-giving, and giving the worker a sense of meaning and positive feeling about her work.

Furthermore, by paying attention to the relationship that emerges between care-giver and care-receiver, the reciprocal nature of care-giving is more clearly seen. Good care is not performed by emotionless workers who do things to passive elders; rather, good care is delivered minimally in the context of a dyad where the outcomes of care practices for all involved must be considered. Because the relationship between the care-giver and care-receiver is often characterized by inequalities of power in terms of knowledge, skill and vulnerability, the moral quality of these relationships is not captured by a contract model of patient care; neither group may be in a position to negotiate the terms of care as equal partners. Rather a fiduciary relationship, one bound by trust that the carer will not exploit the power given to them, is more appropriate (Carse, 1996). Subsequently, questions about what fosters trust between care givers and care receivers such that relationships can be maintained, and what prevents the development of trust, need to be asked.

Here too, the larger socio-political context and policy that flows from this fails to establish and deliver home care practices that prioritize maintaining relationships. Professional norms frown on blurring the boundaries between family and work. Organizational structures, driven by funding requirements, push social care into the interstices of bed and body work. When clients make progress toward intended goals, assuming they have the financial resources to hire home care, they risk losing their current Medicare-reimbursed home care worker to another home care worker. Even though home care workers often argue that what their clients need most is a relationship - - the presence of another person who offers dignity to them by listening to them - - this kind of companionship, argues Stone (2000 b), is seldom the goal of home care agencies. In fact, agencies' rules are designed which attempt to limit the kinds of behaviors characteristic of close relationships (such as gift-giving, sharing stories, or non-sexual touching). As noted earlier, listening and talking are not recognized as legitimate tasks according to reimbursement schedules. In short, organizational survival requires disengagement, distance, and impartiality.

Subsequently, paid care-givers often go "underground" with their care practices, violating rules, standards, and norms in order to provide the kind of care they know to be best based on their relationships with clients. They visit clients whom they know to be vulnerable on their "off-time;" they run errands for client knowing that there is no one else to do such tasks. Conover (1997) recounts the story of home health aide Claudia and her patient Rose. Claudia, exhausted from Rose's predictable evening screaming rituals, looks upon her as she is having a "delirium fit" in her bed. "Normally," says Claudia, "they train you to be so cautious, to wear gloves all the time . . . that didn't seem to be the right thing in this situation . . . you want to stop the baby from crying , so you hug it, you just do it" (p. 23). Drawing upon her care-giving intuitions and experiences, and defying institutional rules about professional behavior, Claudia goes to Rose, lays down next to her with her arms around her, and finally they (and the other neighbors in the apartment complex) are able to sleep. Such behaviors, however, come at a high cost for home care workers. In doing so, "they must also work to fend off feelings of guilt and fears of getting caught, of losing their jobs, and of hurting clients" (Stone, 2000b, p. 111), huge moral burdens that lead good care-givers to abandon their tasks (Wilber and Specht, 1994). Stone (1999) found that workers "talk about caring and their care-giving work almost is if they were engaging in civil disobedience" (p. 67). Rather than addressing the moral conflicts that arise with carework, the usual intervention response is to give more training to care-givers on professional behavior and offer support groups. Such strategies miss the mark, however, "because if we want people to enter and stay in caring jobs, we need to face up to the moral conflicts of caring work and not wish them away with training and support groups" (Stone, 2000b, p. 111). It is precisely this human contact and emotional attachment that make the job worthwhile and the care effective.

Our current arrangements for home care also make maintaining relationships in the context of informal care difficult. Unlike situations with paid care-givers, however, in which agencies attempt, however ineffectively, to protect workers from overinvolvement with families by bureaucratic rules, current policy arrangements give little attention to the extent to which families are overwhelmed by carework and the extent to which such burdens can harm not only the relationship between care-givers and care-receivers, but the web of family members involved in care-giving situations. A number of points have already been made regarding families as default care-givers.[27] A public ethic of care would give critical weight to seeing families as important ends in themselves. Ambivalence about this commitment is seen, for instance, in such public policies as the Family Medical Leave Act, which provides up to 12 weeks of unpaid leave for employees in firms of more than 50 employees to attend to family health needs. Although this policy is well-intentioned and likely useful to some, for employees of small firms and/or employees who cannot afford an unpaid leave, this policy is unhelpful.

Family relationships often give meaning and texture to human relationships. Just as families are usually understood to have obligations to each other, society has moral obligations to families. If, as some conservatives are fond of saying, families

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[27] These points include issues such as the economic value of informal care-giving, objective and subjective burdens of care-givers, typical inteventive responses geared at further education and/or support of care-givers, and inequalities in care arrangements such that women - - and women of color in particular - - are responsible for care-giving.

are truly foundational institutions that embody critical human values, then "society has to ensure that care-giving does not destroy them" (Levine, 1999, p. 348). Levine (1999) argues that "[t]otal self-sacrifice may be ennobled in legend; it is a decidedly unsatisfactory way to live one's life and a poor basis for public policy" (p. 348). As such, the work of family care-givers should be supported through societal norms and various economic supportive measures and incentives. Although the specifics of such measures are complex and contestable,[28] it is not the case, per common intuition, that families will withdraw their free labor in exchange for paid care-givers should this be more readily available. This so-called substitution effect, along with the woodwork effect (that is, people currently doing care work for free will come out of the woodwork and demand payment) are major barriers to expanding public dollars for home care. But numerous empirical studies do not find such displacement to occur (Hanley, Wiener, and Harris, 1991; Linsk, Keigher et al, 1992; Yordi et al, 1997).[29] Families continue to deliver large amounts of unpaid care, and when they do begin to use formal care, they use it to supplant, rather than replace, the care they already provide (Caro and Stern, 1995; Harrow, Tennstedt, and McKinlay, 1995; Tennstedt, Crawford, and McKinlay, 1993; Yordi et al, 1997). To assume that people will readily hand over care work to paid employees if given the opportunity is to assume that care work is simply another form of labor that people do to survive. Such an

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[28] Economic supports are discussed later.

[29] Hanley, Wiener, and Harris (1991) reviewed 53 studies between 1960 and 1988 and found that in only four cases was there a significant decrease in informal care when formal care was made available. Yordi et al (1997) state that this conclusion still held in 1997. Yordi also states, citing a Congressional Budget Office Report, that the concern of displacement was raised already in 1977.

assumption, however, overlooks care work as an expression of basic relatedness, as a way to maintain relationships, and express love. Says Stone (2000 b), "They [caregivers] would no more stop caring for people they love if replacement services became available than they would stop eating if someone offered to eat for them" (p. 20 in Stone). In fact, it is the case that informal care replaces formal care far more than formal care replaces informal care (Foner, 1994; Levine, 1998).

Nursing Home Care

As in home care, the carework that occurs in nursing homes is not directed by the needs of elderly residents but by a larger social and political context. In fact, the details of large-scale aging legislation have more to do with managing the physical needs of the elderly, a function similar to what Piven and Cloward (1993) discuss in regards to the functions of public welfare, and less to do with what the elderly require to preserve their lives and construct meaning out of them. They, like the unemployed or marginally employed, are potentially disruptive, and were their needs as full citizens acknowledged, elemental changes would be needed in the way we organize housing, provide social care, and allocate resources. Diamond argues that our current arrangements for delivering long-term care are grounded in the macropolitical forces of capitalist medicine as a defining principle in nursing home organization.[30] Within this culture, cost-accountable, profitable, medical care is "defined in terms of tasks and abstract management technologies [which] create nursing as a commensurable and cost-accountable process" (Diamond, p. 177). This

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[30] Diamond, for example, intentionally uses the phrase "on Medicaid" rather than "receiving Medicaid" (or Medicare) to reinforce the exchange that occurs between the state and the nursing home while leaving residents penniliess (1992).

political context, one bent on deficit reduction and therefore not open to increased funding of long-term care, along with a market economy that supports a system of investor-owned nursing home corporations rather than national health insurance, translate into care practices that directly shape interactions between care-givers and care-receivers.

While Medicaid, not Medicare, is the primary controlling policy for nursing home care, similar difficulties in care practices in nursing home care as in home care are encountered. This should not be surprising, given that medical, not social, paradigms shape long-term care. These medical paradigms are, as already discussed, grounded in certain understandings of human beings as being normally independent and self-sufficient; when disease or illness strikes, the goal of medicine is to work quickly and effectively to restore one to health and productivity. Henderson (1995) suggests that nursing home residents become "victims of therapeutic expectation but incurable disease" (p. 54). There is no place in public life to recognize frailty and dependence, to recognize the social connections so constituted as care that give life meaning; to construct long term care only in terms of medical care is to not see the entire scope of human need. While acute and often high-tech care with Medicare and Medicaid is supported, resources for assistance with daily activities of living are meager. Ironically, for people who are poor and unable to purchase their needs for care on the market, yet not in need of high tech medical care, we have no options other than to construct their need for care precisely as medical such that they can receive nursing home care. Being old, poor, disabled, and alone is not sufficient reason for receiving care; only medical need can do this for them.

Nursing home difficulties in care practices that mirror difficulties in home care practices also should not be surprising given that, underlying both, there is no settled consensus about who is to provide what level of care. Although Medicare as a federal program is nearly universal to adults age 65 or older, it provides mostly a certain kind of care, that is, medical care, and persons with other or additional kinds of care needs are left to fend for themselves, relying on the market to purchase such care, or on a patchwork of state and local policy initiatives that might provide social care, such as through the Older Americans Act. Medicaid policy also reflects a similar ambivalence about who is to provide what kind of care and how much of it. Individual states shape the Medicaid, Medicaid waiver, and other state-funded programs that subsidize nursing home care, particularly for low-income people. Individual states decide on eligibility levels, program characteristics, payment levels, payment mechanisms, and systems for allocating and monitoring care. States also set their own licensing and regulation rules for nursing homes, determine legislative standards that define the nursing care industry, and determine certificate of need programs to manage the supply of services in the state. Beyond meeting the minimal OBRA 1987 nursing home standards, states are free to set their own standards for levels and quality of service. Thus there is a tremendous range in the level and quality of benefits that elders receive, depending upon where they live. And, while Medicaid has greater flexibility than Medicare in defining need as more than medical care, there is tremendous influence exerted by a variety of special interest groups to shape Medicaid in particular ways. The nursing home industry, for instance, that receives the majority of its funding from Medicaid has powerful political influence in each state to ensure that they retain their position as the dominant long-term care provider.[31] Efforts to increase Medicaid-funded home and community based waivers encounter intense political opposition and raises fears as well about greatly increasing the cost of home care (Harrington, 1984; Kane, Kane, and Ladd, 1998).

The Omnibus Budget Reconciliation Act of 1987 (OBRA 1987) contained within it nursing home regulations that emerged from a series of nursing home reforms in the 1980s; as such, it represented the first major legislative improvements in federal regulation of nursing homes since 1965. The changes introduced in the legislation created new standards for residents' rights, resident assessment, and quality of care. The legislation clarified that widespread use of physical and chemical restraints were inconsistent with a good quality of life. It mandated a 75-hour nurse aide training program, revised the inspection process to require observation and interview of residents and their families, and it developed enforcement policies to take into account the scope and severity of particular care problems (Institute of Medicine, 1986). The federally mandated Resident Assessment Instrument (RAI) was developed to collect uniform data about each resident for use in individualized

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[31] Pear (1997) writes, "while money often buys access to power in Washington, the efforts of the nursing home industry are particularly well-documented" (A16). He goes on to note key fund-raising activities of nursing home directors and large gifts given to the Democratic party directly from the American Health Care Association, the largest nursing home trade association. Harrington (1984), more than a decade earlier, observed that while much of the nursing home industry is private in the sense that it is characterized by tremendous growth in for-profit and chain-owned corporations, it is effectively a public program defined by public policies, particularly Medicaid. In terms of political power, the industry is highly organized, and makes large contributions to political campaigns and lobbying activities: "The associations direct major efforts toward influencing the development of administrative regulations, rates, and licensing activities, and also focus on legislators and their legislative activities" (p. 487).

care planning; it was implemented in every nursing home reimbursed by Medicare and Medicaid in 1989. The RAI includes both the Minimum Data Set (MDS) for resident assessment and the Resident Assessment Protocols (RAPs) for standardized care planning that are triggered by selected MDS items.

The 1987 OBRA regulation and enforcement efforts were expected to bring about significant improvements in the quality of care of nursing home residents. Since its passage, some important gains have been made in the care of institutionalized elderly. More attention is paid to residents' rights (Dubler, 1996). The use of chemical and physical restraints has been reduced. Unfortunately these regulatory efforts have not been sufficient to bring about the hoped-for changes (Diamond, 1992; Engle, Fox-Hill, and Graney,1998; Graney and Engle, 2000; Ouslander, 1997). According to Harrington (1999), 1995 data on nursing home deficiencies indicate that the top ten deficiencies reported in nursing homes are the same deficiencies prevalent in nursing home care since 1975; these problems, furthermore, have not improved since 1995.[32] These problems point to severe shortcomings in care practices between care-givers and care-receivers, concerns that have not been adequately addressed by public policies of Medicare or Medicaid, or by regulatory prescriptions of the likes of the 1987 OBRA.

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[32] The top ten deficiencies in U.S. nursing homes in 1995 were failures to conduct comprehensive resident assessment, ensure sanitary food, prepare comprehensive resident care plans, deliver care that protects the dignity of the residents, remove accident hazards, prevent inappropriate use of physical restraints, prevent pressure sores, provide adequate housekeeping, accommodate the needs of residents, and insure infection control (Harrington, 1999).

Nursing Home Care and an Ethic of Care: From an ethic of care, as with home care, we see that policy and organizational practice fails to affirm a social conception of the self, to be contextual, and to prioritize relationships.

Social conception of self: Policy that shapes and delivers nursing home care struggles with establishing policy that affirms a social conception of the self. As with home care, we see that medical paradigms are privileged within nursing home contexts such that residents are known primarily as their diseases and impairments. These disease and disability diagnoses determine residents' identities as patients, imputing meaning to their behaviors. Diamond (1992) notes, for instance, that a crying person is understood to be crying because she has Alzheimer disease, not because there might be other reasons for her tears. As well, basic caring tasks and their related problems are "transformed into its own measure of health care: hunger into nutrition, air into chemical sanitation, showers into a schedule of cleaning, restraints into day room coverage . . . (Diamond, 1992, p. 207). The process of medicalization is operationalized by the endless charting protocols required for compliance (1987 OBRA) and payment (Medicare, Medicaid, and third-party reimbursers). Diamond writes:

> In separate slots on the shelves behind the nurses' station, were filed the charts of the residents. Each person had her or his own record, beginning with diagnosis, followed by medical consultations, prescriptions, vital signs, weights and other physical measurements, and behavior. The process of charting treated the residents as individual entities isolated from the personal relationships within which they were enmeshed in daily life. In the charts, the

> formal records of their existence, they were taken out of their local contexts and the relationships that were an indispensable part of their everyday survival strategies. In the documents they became patients, identified by their pathologies . . . . In the charts none of the actual interactional stories that contextualized these days and nights came through. The settings vanished, overridden by cases: patients, diseases, medicines, and measurements. The process involved the ongoing creation of phenomena the organization could service" (p. 121 – 122).

In a similar vein, William Thomas, creator of the Eden Alternative notion of nursing home care, argues that a flawed definition of care, that is, care equals medical treatment, underlies the management of contemporary nursing home care. In this context, the focus of care and the allocation of resources is on diagnosis and treatment of disease with the end result being that residents are "bloated with therapy and starving for care" (1996, p. 20).

When nursing home care is conflated with medical care, and residents become patients, other dimensions of need and other dimensions of self are pushed into the periphery. Sarton's (1973) fictional account of Caro Spencer, an elderly resident in a rural nursing home called Twin Elms, gives understanding to the difficulties of preserving a sense of self within a nursing home context. Sarton writes,

> I am forcing myself to get everything clear in my mind by writing it down so I know where I am at. There is no reality now except that I can sustain inside me. My memory is failing. I have to hang on to every scrap of information I have to keep my sanity, and it is for that purpose that I am keeping a journal.

> By the time I finish it I shall be dead. I want to be ready, to have gathered everything together and sorted it out, as if I were preparing for a great final journey. I intend to make myself whole here in this Hell. It is the thing that is set before me to do . So, in a way, this path inward and back into the past is like a map, the map of my world. If I can draw it accurately, I shall know where I am (p. 14).

Thomas (1996) argues that while acute medical care is readily available, loneliness, helplessness, and boredom constitute the everyday misery of residents. Time constraints prevent nurses aides from the talking and listening tasks of care as such acts are not recognized as "chartable" activities; Diamond, for instance, is scolded for sitting down with a crying Mary Karney. He writes,

> . . . To stay to give Mary Karney an emotional outlet for her trouble was supplanted by the act of taking vitals and moving on. Who was the giver and who the taker got confusing as I kept taking Mary's vitals. Tasks produced numbers that, rather than folded in as part of human relations, were extracted out as though they stood apart; then they dictated the form that interaction took between staff and residents (1992, p. 159).

Loucks (2000) recounts the failure of a kind and solicitous neurologist to recognize that her mother is more than her recent stroke. In the moment of being asked by the neurologist, "who is this person" (in reference to the adult daughter), the elderly mother can recall neither the name of her daughter or the word "daughter" to describe the relationship. In an attempt to inject humor into the situation, the mother calls the daughter "Periwinkle." The daughter immediately recognizes her mother's response as humor, as her mother's attempt to overcome frustration and embarrassment; the neurologist, however, uses the interaction to confirm the mother's mental status as confused. All of these disparate accounts are joined together by a common theme of being narrowly defined in expert medical terms, while other important dimensions of self are subverted.

Using physical care as the gold standard for measuring quality of life in nursing homes, "psychosocial care was a footnote grudgingly delivered in muted forms" through various sorts of activities (Henderson, 1995, p. 38 – 39). Even though psychosocial activities held promise for supporting and sustaining a social conception of the self, Henderson noted the distinction between meaningful and counterfeit activities. Meaningful psychosocial activities, such as a fishing outing, were highly successful for residents as judged by their eagerness to participate and the countless stories generated by participants about the day's outing that continued for over a year after the event. Because the event was of low visibility to the community, however, and therefore not successful in generating a positive public face, it was not repeated. In contrast, activities that attached to religious or civil categories, such as Christmas, Easter, or Mother's Day, were conspicuous and lavish in their public celebrations, fostering positive community relations and increasing the stature of the organization in the community. Yet the events themselves for residents generated nowhere near the enthusiasm of the fishing trip, and all talk of the events vanished within weeks after the events. Even though all of these events were entered as "activities" in nursing home care reporting forms, only one outing, the fishing trip, was judged to be meaningful by the residents. Diamond (1992) suggests that the "social production of activities bore a certain resemblance to the social order of food and cleanliness. Directed by those in authority, who did not live there, activities were presented to recipients, those acted upon, who tried to make sense of the social order that had been created elsewhere" (p. 97). Furthermore, communication skills, a component of psychosocial care, is also devalued, given little or no currency on the required "to do" list; "the actual subtleties and skills related to providing psychosocial care were reduced to congenial behavior, with no formal evaluation. There is no perceived need to truly upgrade staff psychosocial care skills. There was no reward for it" (p. 46). In short, the benefits of psychosocial care were invisible to residents and staff. Henderson notes that in his ethnographic study, there was "no staff member who is trained to be perceptive of the psychosocial environment, while conversely there are plenty of staff members who have received formal education in business management and medical-model nursing" (p. 53).[33] What counts as legitimate care are those medical actions promoted and rewarded by federal and state regulations and detailed in medical charts.

In addition to marginalizing emotional and psychosocial care, even the most basic acts of care are commodified and medicalized such that they can fit into a system of health care arranged to turn a profit for those in charge and be purchased by those with resources. As noted earlier, 62.5 percent of U. S. nursing home residents have illnesses or conditions related to dehydration (Kayser-Jones, Schell, et al 1999);

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[33] Given that a key role for social workers in nursing home settings would seem to one of attending to the psychosocial environment, one wonders if there was a social worker in Henderson's agency and if so, why he or she was not more visible in the psychosocial realm.

35 to 85 percent of U. S. nursing home residents were malnourished (Burger, Kayser-Jones, and Bell, 2000). Residents' chronic illnesses, pressure ulcers, and infections are poorly managed due to financial incentives that reward transfers of patients to acute care hospitals and discourage geriatricians from practicing in nursing homes (Boult, 1999). Nurses and aides are under considerable pressure to accomplish more tasks than they are reasonably allotted time for and are often without the necessary supplies to perform their duties effectively and appropriately. Furthermore, the language of care-giving is cut from the required training process for nurse aides, and the focus is on biological and physical aspects of the work only. Diamond writes:

> The formal knowledge became privatized, to be purchased for tuition, while conceived and judged by medical, corporate, and state administrators. In this sense the training curriculum was not separate from the overall commercialization of nursing home care, but was an integral part of it; what was only part of the work, the science and measurements, was taught and sold to the students as its whole (1992, p. 185).

All of this points to a system that is weighted more heavily toward financial productivity and grounded in curing and restoration to health than it is toward wholistic, attentive, quality care of frail elderly people.

Care-receivers' responses to limited and inattentive care are evident. Diamond (1992) described how through close and intimate interaction with residents he became aware that they were far more than passive recipients of health care goods and services. Residents who sensed good faith efforts from care-givers went to lengths to assist them in their hard work. Some attempted to give workers monetary tips for extra efforts, expressed concerns about their well-being, and instructed workers in how best to care for them. Conversely, some residents who perceived care-givers to be harsh or uncaring used subtle but effective behaviors, such as purposeful incontinence at the end of a shift to make a worker stay longer, to demonstrate their displeasure with the care-giver. Louck (2000) observed that patients frequently lashed out or cried in their attempts to resist restraints or feeding; for some, when these efforts failed, residents used dissociation to cope with invasive routines of nursing home care. In their analysis of three qualitative studies of adult care-receivers, Russel, Bunting, and Gregory (1997) found that care-receivers developed and used a variety of protective care strategies. These strategies not only protected themselves from excessive or inadequate care, but also tried to protect care-givers from perceived undesirable parts of care-giving. Careful attention to how care-receivers shape and respond to care-giving efforts is essential, the authors conclude, to ensuring that "the creativity and work of CRs [care-receivers] is recognized and used wisely" and to prevent unwitting construction of barriers that make the lives of care-receivers more difficult and stressful (Russel, Bunting, and Gregory, 1997, p. 540).

An ethic of care's attention to affirming a social conception of the self extends to paid care-givers as well as care-receivers. We must ask whether paid care-givers have in place the necessary social conditions such that their autonomy is not compromised by the work they do. Here it is seen that larger societal constructions of what kind of work is valued and organizational arrangements for care-giving impede the abilities of careworkers to care for themselves and their care-receivers. The larger societal ethos is one that generally devalues care work, and devalues (or romanticizes) women and mothering. As discussed earlier, values that affirm independence and self-reliance constitute the principal public discourse in our culture, with dependency and frailty relegated to the private sphere of women's work such that it becomes easier to deny that we need the help of others and they need us. England and Folbre (1999) note that care work, even after statistical adjustment for other job characteristics known to affect pay (such as educational requirements, union membership, and physical demands) pays less than other kinds of work. In their analysis of why this is so, they argue that the coding of skills typically done by women are not recognized as valuable contributions; thus low wages are not surprising. Additionally, some see such caring skills as intrinsic to women, something they come by "naturally" and from which they draw great satisfaction. Hence, given such rewards, decent pay is not necessary.[34] Furthermore, in a culture of individualism, we blame the poor for their problems, including problems of dependency and frailty, and we are unwilling to pay those who perform caring labor for those who cannot afford to meet their own needs for care on the market. The impact of low wages influenced by this kind of thinking, however, is that paid care-givers are barely able to meet their own sufficiency needs. For some, their yearly salary is below the federally established poverty line. If they are parents, they must

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[34] The logic that because caring work attracts people with caring motivations who can then be paid less is obviously flawed. This suggests that we would then pay people who fill onerous jobs more, a practice that does not occur. Furthermore, most people are attracted to work that is somehow satisfying. People who are accomplished at using their minds are drawn to intellectually stimulating work; it does not follow that they are penalized for this in terms of pay.

leave their own children in sometimes precarious care situations when they go to work. They must often work two jobs to make ends meet, thus having little time or energy to enjoy their own families or the activities that for many give meaning to life (Louck, 2000; R. Stone, 2000; Weinberg, 1999).

Organizational arrangements also impede care-givers' autonomy. In addition to low wages and inadequate benefits, other identified stressors include the intensity of constant human interaction with little control over outcomes, little involvement in care planning or coordinating, constant staff shortages, and few paths for upward mobility (Banaszek-Holl and Hines, 1996; Harrington, Zimmerman, et al, 2000; Schirm , Albanese, et al, 2000).[35] Physical problems of low-back pain, headaches, and dizziness result from efficiency reports that underestimate the number of workers needed to do particular jobs within certain time constraints (Diamond, 1992). Paid care-givers, like care-receivers, bemoan the lack of value given to basic tasks of talking and listening, comforting, holding, and simply being present (Louck, 2000). Such working conditions reinforce the notion of privileged irresponsibility; those closest to care-giving situations have little control over care practices and responding appropriately, while those at a distance - - owners of for-profit operations and policymakers, for instance - - put in place complex and cumbersome rules and regulations designed to maximize profit and efficiency and minimize "waste" and "non-essential" care. Williams (1996) astutely observes that "residents will never have more autonomy or self-respect than that which nursing home managers grant their employees" (p. 70).

Contextual care practices: As with home care, the larger socio-political context, and the policies that flow from this create difficulties in establishing practices that allow for contextual care. Ideally, the care-giving relationship would be foundational to making decisions about how best to care for nursing home residents. The Medicare regulations (and by extension, Medicaid regulations) discussed earlier that influence the contextual nature of care practices in home care also apply in nursing home care. Bureaucratic and professional norms also create similar tensions for relationships between care-givers and care-receivers in nursing homes as they do for care practices in home care.

Nursing home residents' lives are shaped by norms that emphasize efficiency, cost-effectiveness, and restoration of health.[36] Residents' lives are shaped by rigid routines designed for staff and operational efficiency. These routines govern ordinary happenings: getting up in the morning, choosing and eating meals, personal care, arranging to meet friends, and sometimes getting to the toilet. Regulatory rules in place, while designed to protect frail elders, limit personal freedom. Interpretations of these rules sometimes prevent even cognitively alert residents from taking their own over-the-counter medications, storing food in their rooms, or re-arranging their furniture.

This routinized life is lived largely in public view and crowded spaces. Residents share double rooms with strangers, often a succession of strangers. Limited

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[35] See Banaszek-Holl and Hines (1996) for a helpful review of the literature in terms of this point prior to 1996.

[36] Ethnographic studies convincingly make this point; see, for instance, Diamond (1992), Foner (1994), Gubrium (1975, 1993), and Schmidt (1990).

space requires that residents take only their most valued possessions with them, even though personal possessions cannot be safely guarded. Communication with those outside of the facility can be difficult to arrange, particularly if one has to depend on someone else to place a phone call or write a letter.

Nursing home rules and regulations are cast to those residents most impaired with insufficient regard for those who are cognitively alert. As noted earlier, maintaining a sense of personal identity is a major struggle in such a setting (Tobin, 1991). Even though perceived control and choice over the events of one's life is positively correlated with physical and mental health and inversely correlated with death, standard nursing home treatment seems to put a sense of control in jeopardy (Kane, Caplan, et al., 1997). Kane, Caplan, et. al. found that nursing home residents and nursing assistants attach deep importance to having control and choice over everyday matters. They differed, however, in the relative weightings of choice items with residents valuing having control over matters relating to maintaining an identity outside of the nursing home - - such as being able to make short trips away, using the telephone, and getting mail - - ranked most important to residents. They were much less concerned with activities within the home, an area that nursing assistants thought they would find important. This suggests "that the niceties of ordinary life take precedence over a carefully designed therapeutic community, replete with art therapy, music therapy, conversation therapy, and so on" (p. 1092). One study found that, within nursing homes, administrators' perceptions of the value choices of residents and residents' value choices were not in agreement 70 percent of the time. Beyond the struggle of maintaining a personal identity, this misunderstanding can "contribute to an inappropriate allocation of human, fiscal, and physical resources" (Knox and Upchurch, 1992, p. 10). Such a setting certainly is not a setting conducive to identifying and meeting needs grounded in a relationship between care-givers and care-receivers.

More specifically in terms of nursing home care, the effects of the 1987 OBRA are useful to consider in terms of delivering care that responds to the unique and individualized needs of care-receivers. The goal of the Resident Assessment Instrument (RAI), an outcome of the 1987 OBRA, was to provide a universal tool for resident assessment via the Minimum Data Set (MDS) and standardized care planning via the Resident Assessment Protocols (RAPs). Implemented in all Medicare and Medicaid-reimbursed nursing homes in 1989, the RAI has proven to be a complex and time consuming task for staff to complete. The admission MDS contains 450 assessment items and the quarterly contains 250 items; about one-half of these items trigger RAPs for care planning. The MDS is intended to be based on multiple assessments across time (ranging from 7 days to 90 days) and multiple sources (such as staff, family members, residents, and consultants). It takes anywhere from one to ten hours to complete a single MDS, hence requiring large amounts of staff time, and generates massive amounts of paperwork for just one resident (Teresi and Holmes, 1992).

The resources required to complete the MDS and RAI are often viewed as unnecessary or of less priority when contrasted to the immediate demands of patient care (Brooks, 1996; Ouslander, 1994, 1997). To save time, nursing home staff sometime make their assessments at a single point in time or not score items as positive that would trigger RAP care planning. Through such shortcuts, the "accuracy of the MDS assessments, the appropriateness of subsequent care planning activities, and the reimbursement of care may all be compromised . . . defeating the intent of OBRA" (Graney and Engle, 2000, p. 583). On the other hand, lack of complete documentation leads to citations by regulators, which is also a serious concern to nursing home administrators. Completing a detailed assessment of patients using the RAI in tandem with two hours of clinical supervision per month focused on individualized care planning, does indeed lead to care-givers being more knowledgeable about their patients, having a heightened awareness of their patients as unique persons, being more aware of their patients' remaining resources, and more empathic to the experiences of family care-givers - - all hoped for goals of the initial RAI (Hanesbo and Kihlgren, 2000). Such intended outcomes occur, however, according to Hanesbo and Kihlgren, only when care-givers are provided with the necessary time for completing detailed assessments and have ongoing supervision in care planning.

While the demands of the RAI often preclude developing individualized care plans, others have noted further additional limitations in the usefulness of the RAIs. Patient self-reporting on some items, most notably pain, is absent; only nurse evaluation is used to assess frequency and location of pain on the MDS. Furthermore, some questions, again pain most notably, do not trigger RAPs for further assessment and planning. Subsequently, there is no follow-up evaluation on the efficacy of medication given to a resident. Finally, some important coping mechanisms are absent from the list of assessment items on the MDS. Examples of these include religion and its effects on shaping the ways residents respond to suffering and death, and strategies one has used to maintain health and find meaning over the course of one's life (Engle, Fox-Hill, and Graney, 1998). These examples point to important contextual facets of one's life history that continue to shape the subjective meanings of quality of care - - variables that go well beyond medical constructions of health - - for those likely to finish out their lives in a nursing home (Gubrium, 1995).

Others note that the process of evaluation brought about by the 1987 OBRA is inherently flawed; as such, it works against an ethic of care's emphasis upon care practices that arise out of context and prioritizes instead rationalization and objectification. Gubrium argues that although "a quality assurance industry has emerged to design assessment instruments, offer data management services, and monitor results and compliance activity" (p. 32 – 33), living one's life according to a care plan creates "few opportunities [for nursing home residents] to exercise choices that are meaningful in the context of their own lives and their frameworks of meaning" (p. 42). Diamond's (1992) work is illustrative here. He points to the loss of collective rituals in institutional care, such as there being no public forum or formal rituals in which to mourn the dead in the nursing homes where he worked. The desires of residents to meet their own needs or desires were out of their control. Being able to purchase a small refrigerator for one's room was prohibited by distant public health rules; being able to obtain cold medication or aspirin was impossible because it was not prescribed by an absent doctor. Simple tending acts were pared to the minimum because of insufficient staff deemed sufficient by management time studies in efficiency. Diamond notes: "If the orders from the rational plan had parceled out the tasks into a time-motion calculus that made sense in the abstract, carrying out the orders continually came up against the unplanned, fluid, and contingent nature of everyday tending" (1992, p. 143). Feeding a frail sick person "seemed one of the most refined nursing skills of the day as I watched a seasoned nursing assistant sensitive to the slow pace of an old person's eating, knowing how to vary portions and tastes, how to reinforce nonverbally while feeding - - a refined and complicated skill, but unnamed and suppressed when forced into a forty-minute task" (p. 134).

Subsequently, while the goals of the 1987 OBRA reform were well-intentioned, they have not resulted in care practices that arise out of individualized and concrete knowledge of the needs of care-receivers. This is not surprising, given that the OBRA reform efforts, like regulations for Medicare's home care benefit, identify the wrong targets for change. The 1987 OBRA, like Medicare regulations, emphasized more training, stricter rules, and greater regulation of care-givers, ironically the target group who has least to do with the problems inherent in providing quality long-term care. The 1987 OBRA leave untouched structural factors such as insufficient staff, low wages and inadequate benefits, and payment systems that reward high-tech acute care. These structural problems continue to persist because we are unable or unwilling to recognize care as a critical and basic need and as such, restructure social and economic institutions to support the best of caring practices.

Prioritizing relationships: Just as it is difficult to affirm a social conception of self and provide care that is contextual given current arrangements, it is also difficult to prioritize relationships within nursing home settings. The reasons for this are implicit in the discussion above. Public policies and regulations as well as organizational structures for implementing and delivering care are arranged around other criteria than meeting the needs of frail elders.

In Diamond's analysis of nursing homes (1992), good care is blocked by a capitalist push for profits as well as bureaucratic state regulations that privilege scientific, medical knowledge. Capitalism undermines care by cutting down on the time allocated for emotional care and through increasing privatization. Care has become a premium, "a privilege for those who can pay the price, rather than a right of citizenship" (p. 201). State regulations undermine care by requiring extensive and unnecessary paperwork documentation to meet the demands of external regulations. These regulations are based on scientific and medical models of care that devalue emotional care by not reimbursing it, and thus rendering it invisible. Foner's (1994) analysis examines bureaucratic hierarchies oriented to efficiency, impersonal rules and standards, prescriptions of formal procedures and schedules, and technical training. Workers operate on the basis of standardized techniques; record keeping reduces the complexity of care-giving into precise, measurable, and quantifiable units of service. These arrangements, argues Foner, preclude attentive and relational care because for such to occur, authority needs to be decentralized and routines must be flexible to respond quickly and effectively to individuals; training in interpersonal relations is essential. Similarly, Abel and Nelson (1990) argue that the particularized and unpredictable nature of carework fits uneasily into bureaucratic structures.

When care is commodified and bureaucratized, residents are turned into patients (or "beds") and the work of care is parceled out into quantifiable tasks.

Goods and services are measured and priced such that owners of nursing homes can achieve a profit for themselves and their shareholders. As well, these stakeholders, not residents, define what constitutes good care. Cleanliness and nutrition, for instance, are evaluated by the completion of discrete tasks (diapering, showering) or units of measure (amount of liquids and solids consumed per meal; units of nutrition). Such things as taste, texture, water temperature of the shower, or desire not to be diapered are irrelevant to formal check-offs on quality of care documentation. Those who live and work in nursing homes are transformed from people who give and receive care to goods and services that bring a profit, into commodities and cost-accountable units. Labor-cutting strategies, such as hiring people to come in for meal time feeding, hiring part-time people, or using restraints instead of people for supervision, are implemented. Staff-resident ratio become determined not by the needs of patients or workers, those closest to the work of caring, but rather conform to industrial forms of production.

In this context, relationships become transformed. At administrative levels, residents as patients "become adversaries rather than occasions for compassion and intimacy" (D. Stone, 1997, p. 551).[37] In fact, complex gatekeeping systems work to admit "paying" patients, that is, those who can pay privately or have sufficient Medigap policies to cover costs, while working to screen out Medicaid patients (Meyer and Storbakken, 2000). Medicaid-dependent residents are constructed as "welfare cases," as persons who have lacked the foresight or will to save prudently

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[37] Although Stone is speaking here specifically to the relationship between physicians in managed care companies and their patients, her point is well-taken in terms of the dynamics within nursing home administration.

for their future long-term care needs, and thus now drain the Medicaid system and redirect funds away from more needy children.[38] Paid care-givers, particularly nurse aides, find themselves in situations akin to paid home care workers. They are closest to the care-giving situation, understand well the need for holistic care, and yet have no authority to do what they see best for patients without risking reprimand. They, like home care workers, must learn to balance large moral burdens in their care-giving. Ironically, such workers achieve status only by leaving behind the bed and body tasks, becoming supervisors or administrators with commensurate education, and relegating the physical work to others.

Residents as patients, as noted earlier, are not passive about the particulars of such care. Their responses, however, are limited in their effectiveness and targeted primarily at line-staff care-givers, those whom have the least control over care practices. The daily lived experiences of residents are translated into formal documents where specific tasks and procedures are abstracted out of the context of residents' lives. These documents, in turn, become the basis for external evaluation and control. Diamond notes that "outsiders came to judge the inside through methods and criteria that remained outside, while those inside remained outside any evaluation. Those inside were placed outside the boundaries of the privileged communication about them, locked out by the documents that turned the key" (p. 192).

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[38] Such a construal overlooks, of course, the fact that many Medicaid recipients in nursing home settings are poor women who have spent most of their adolescent and adults lives caring informally for others.

In short, failing to recognize that selves are socially constituted results in both care-givers and care-receivers suffering in the relationship. The depth and richness of care-receivers' lives are narrowly constructed to fit medical paradigms and for-profit health care systems. Persons come to be understood primarily in terms of outcomes: performance is assessed in line with strategic aims, heroic actions are employed apart from their relationship to the aims of human flourishing or health, and the daily practices needed to sustain relationships are overlooked (Benner and Gordon, 1996). Care-givers - - usually already vulnerable given the variables of gender, ethnicity, and class - - find themselves further diminished within organizations that exploit their labor and their compassion and minimize their expertise in carework. Surely in a society as rich in resources as the United States, the well-being of one person for another in caring for each other need not be traded. Surely organizations can be developed that foster attentiveness and responsiveness to care receivers' well-being, and systems of financial and professional reward for technological procedures over time taken to communicate effectively with elders can be critically challenged (Carse, 1996).

PART THREE
RE-VISIONING LONG-TERM CARE
INFORMED BY A PUBLIC ETHIC OF CARE

Chapter Six
Caring About and Caring For:
Re-visioning Long-Term Care Through a Public Ethic of Care

In Part II the suggestion is made, but not developed, that long -term care informed by a public ethic of care can help us reconceptualize an alternative vision of long-term care based upon care as a central social and political construct. Part Three develops such a vision. The large question addressed here is this: How might an intentional commitment to a public ethic of care shape long-term care policy and the programs and services which develop from these. To develop this response, several important issues must be addressed.

Our current system of long-term care falls short in terms of conceptualizing and delivering long-term care congruent with a public ethic of care. Long-term care informed by a public ethic of care, following from the discussion of chapters four and five, would be different from current long-term care in several respects. First, our system of long term care would be grounded in meeting the needs of frail elders; the system would not be designed primarily around the economics of providing long-term care.[1] Second, intentional lines of responsibility that are congruent with the assumptions undergirding a public ethic of care in caring for the frail elderly would be addressed; these practices will be the result of understanding responsibilities to care as embedded in cultural and democratic participatory processes.[2] Third, the

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[1] This corresponds roughly to Tronto's (1994) first phase of "caring about."

[2] This corresponds roughly to Tronto's (1994) second phase of "caring for."

policies that flow from the discussion of the first two points will establish and deliver opportunities in concrete situations of care-giving and care-receiving that respond to individual needs, are contextual, and affirm a social conception of the self.[3] The discussion of each of these points as markers of long-term care informed by a public ethic of care will be concretized by attention to specific exemplars. The Oregon Basic Health Services Act, followed by the Oregon Health Plan, and the processes by which these came to be is useful in considering how to ground long-term care in the needs of frail elders and determine how moral responsibilities emerge out of concrete, cultural practices. Two long-term care programs and their respective policies, Programs of All-Inclusive Care for the Elderly (PACE) and the Eden Alternative, are useful to consider in the context of specific care-giving and care-receiving concerns.

Caring About: Meeting the Needs of Frail Elders

To say that a system of long-term care should be intentionally designed to meet the needs of frail elders requires that we consider first what counts as a legitimate need. This is an exceedingly difficult task for several reasons. First, it presumes that we have a shared view of what old age ought to be about, and more concretely, presumes that we share a common understanding of the goals of health and social care for the frail elderly.

It seems unlikely for either elders or their families that this is the case. We know for instance, in terms of health care, that while some frail elders advocate for improving the quality of life over the extension of days in old age, not all agree,

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[3] This corresponds roughly to Tronto's (1994) third and fourth phases of "care-giving" and "care-receiving." This third issue, along with exemplars, is addressed in the Chapter Seven.

and indeed, some request invasive, non-beneficial, or medially futile treatment in the face of death.[4] Cicirelli (1998), surveying people between the ages of 60 and 100 about their preferences for end-of-life care, reports that just over one half of respondents wanted to continue living for as long as possible, regardless of the quality of their lives or their terminal status. By contrast, thirty percent of the elders stated that they would prefer to take active steps towards ending their lives under conditions where they perceived low quality of life. Differences in valuing quality of life over length of life also appears correlated with race. Blacks, relative to whites, are more willing to use life-prolonging technology and less resistant to limiting medical treatment (Caralis, Davis, et. al, 1993; Garrett, Harris, Norburn, Patrick, and Danis, 1993; Lichenstein, Alcser, Corning, Bachman, and Doukas, 1997).

Neither is there strong consensus on where frail elders prefer to receive care. In spite of what seems to be a common perception, certainly supported in part by the professional literature, that frail elders prefer to be cared for at home, this preference is mediated by status ("terminally ill" or "likely to recover") and anticipated extent of disability and consequent need for care. Fried, van Doorn, et. al. (1999) found that in their sample of patients diagnosed with either congestive heart failure, chronic obstructive pulmonary disease, or pneumonia, 48 percent preferred terminal care in

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[4] See Miles (1991) for an account of 85- year old Helga Wanglie's family's request to continue her life with respirator support even though such support was deemed to be non-beneficial. See Callahan (1987, 1990, 1998) as an advocate for improving the quality of life rather than extending days of life in old age. Callahan suggests that all out efforts to extend life at the margins are contrary to the aims of medicine and prohibit attention to the true needs of the elderly for companionship, long-term care, and decent housing.

the hospital and 43 percent preferred terminal care at home.[5] When recovery from illness was likely, 32 percent of those originally choosing home care in a terminal situation preferred hospital care in a non-terminal situation. Among those who preferred hospital care in a terminal situation, 35 percent switched to preferring home care in a non-terminal situation. Subsequent qualitative interviews with respondents revealed concerns about burdening families and incompetent care delivered in the home for those choosing hospital settings, and the desire to be surrounded by family and friends for those choosing home care. Interestingly, when respondents were not confined to either hospital or home care, "nursing home" became a frequent response as to the site where one wishes to receive care.[6]

Second, determining what counts as a legitimate need is difficult because our needs for caring are limitless, infinitely expansive, and constantly shifting; understanding of what constitutes a need depends upon historical, cultural, and technological circumstances. Callahan (1998) observes that with the exception of birth control pills, each of the medical technologies developed since 1950 have had the most significant impact on people over the age of 50. New technological advances, while having only a modest effect on expenditures initially, are refined and more heavily utilized over time, particularly among the elderly (Fuchs, 1999). Recently, for instance, Left Ventricular Assist Devices (LVADs) have been developed; these devices strengthen the part of the heart that is failing when patients

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[5] Participants were selected on the basis of diagnosis, not life expectancy. Nine percent were uncertain about where they would prefer to receive care. Preferences for site of care were not associated with age, sex, ethnicity, education, diagnosis, or functional status.

[6] "Frequent" is not quantified in the report.

are in congestive heart failure (CHF) and add an estimated extra year or two of life. The anticipated demand for LVADs is estimated at about 200,000 patients per year (most over the age of 65), and the costs of implementing one of these devices is between $100,000 and $140,000.[7] If LVADs become defined as a need to which all CHF patients are entitled, an additional $20 to $28 billion per year is added to our health care budget; if such expenses are determined to be covered by Medicare, Medicare's budget will assume most of these costs, and in the absence of increased taxes to support greater public outlays, this money will be taken from supporting other perceived legitimate needs.

Finally, determining what counts as a legitimate need is difficult because needs are historically and culturally constructed and shaped. Walzer (1983) notes that needs are always contextual, relative to political power, history, and culture. He writes:

> Despite the inherent forcefulness of the word, needs are elusive. People don't just have needs, they have ideas about their needs; they have priorities, they have degrees of needs; and these priorities and degrees are related not only to their human nature but also to their history and culture. Since resources are always scarce, hard choices have to be made. I suspect that these are and can only be political choices (p. 66).

Walzer's assertion is supported with a convincing example of the historical development of health care services. In medieval times, health care was not a need

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[7] This example was provided by Professor Leonard Fleck in an email conversation, July 1999.

because it was relatively ineffectual. What was perceived as needed then was salvation; one's soul was in need of eternal life. Consequently, churches with regular worship services were in every parish, the young were catechized, and communion was compulsory. The "cure of souls was public" and every effort was taken to ensure that each person had an equal chance for salvation and eternal life (1983, p. 87). Today, among modern citizens, "longevity is a socially recognized need" (p. 87). Between the transformation of the medieval need for curing souls and modern needs for longevity is, of course, a long history marked by an increasing emphasis in medicine and technology upon the scientific method for healing. Medicine and technology's undertakings and their successes resulted in the construction of actual social and medical needs deemed necessary for human flourishing, and in turn, continue to propel scientific research for cures to maladies that are named as medical problems. To sum, there is "no *a priori* stipulation of what needs ought to be recognized [as] possible" (p. 91).

Even if we were to have some consensus regarding what constitutes a legitimate need, meeting such needs is difficult because not all legitimate needs can be met with public funds. Health and long – term care for the elderly have long been recognized as the "black hole" of state budgets; we have already seen how Medicare and Medicaid expenditures for care of elders continues to rise. Subsequently, it is no surprise that state and federal governments engage in their fiscal tug of war over who should pay what for frail elders. Difficult decisions regarding cost containment and rationing must be made, but in the absence of any public discussion of how best to care about and care for frail elders, the family by default continues to assume increasingly greater responsibility for the care of frail elders, and the market increasingly defines such care as commodities available for purchase rather than a moral responsibility in which we are called to consider how best we can care for each other.

To summarize, a system of long-term care informed by an ethic of care requires that to care about frail elders, the meeting of needs is central and such a system should be intentionally designed to meet the needs of frail elders as they define them. As discussed, this is difficult because it presumes we share a common understanding of the goals of health and social care for the frail elderly, because our need for care is infinitely expansive, shaped by historical, cultural, and technological circumstances. Given limited public resources, some needs inevitably will go unmet. How then, assuming we want to design a system of long-term term care informed by a public ethic of care, should we go about determining what needs count as legitimate, and how will we decide among legitimate needs those that we will meet as a matter of public responsibility? Shortly the argument will be made that the resources of democratic deliberation are essential to addressing the question of needs. First, however, the concern of understanding and meeting responsibilities - - caring for- -in a manner that accords with the assumptions undergirding a public ethic of care must be addressed.

Caring For: Determining and Assuming Responsibility for Meeting Needs

Long-term care informed by a public ethic of care would be grounded in meeting the needs of frail elders. As well, intentional lines of responsibility that are congruent with the assumptions undergirding a public ethic of care in caring for the frail elderly would be addressed. Chapter Four discussed the difficulties in understanding responsibilities as grounded in formal obligations. With the exception of wage earners who contribute to their future needs for economic security and health care through FICA, public policy built upon such understandings has been unwilling to accept responsibility for citizens' dependencies except in the most grudging of circumstances. Persons in need of long-term care have had to rely on family (where such needs are hidden from public view), purchase care on the market (where it is constructed as a commodified item), or rely on Medicare for acute care (with its assumptions that one can be restored to health and independent functioning). If none of these are available to someone, then one can turn to stigmatized welfare programs.

A public ethic of care, argues Tronto (1994), would be grounded not in formal obligations to which autonomous people freely commit, but rather understood as imbedded in cultural practices and political processes. Although she does not develop the idea of responsibility as embedded in cultural practices and political processes to any great extent, her ideas are congruent with the work of Margaret Walker (1998).[8] Walker's understanding of responsibility can do practical work for a public ethic of care in long-term care, both as a way to understand needs and understand responsibilities. Hence it is important to summarize her work.

In *Moral Understandings* (1998), Walker argues that morality itself consists in practices, not theories. Walker argues against what she call a theoretical-juridical

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[8] An email conversation with Tronto on November 14, 2000 confirmed Tronto's understanding of responsibility as congruent with Walker's ideas.

model of morality and moral theory.[9] In contrast to this, Walker (1998) develops an alternative model, the expressive-collaborative model. On this account, morality consists of practices that arise and occur between people from which people learn that they are responsible to others and for things. The theory of morality "is an attempt to understand these practices . . . [the theory] attempts to find out what people are doing in bringing moral evaluation to bear (in judgment, feeling, and response) on what they and others do and care about, and whether some ways of doing what they are doing are better ways than others" (p. 15).

In Walker's account, moral justification is understood as a kind of equilibrium among people that can survive the transparency of reflection.[10] Conceived of as "social negotiation in time," members of a community try to harmonize actions and

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[9] Within this model, codifiable and compact sets of procedures can be applied by any agent to a given situation to produce a justified and determinate action-guiding principle. This model assumes that morality is essentially knowledge, that the core of this knowledge is essentially theoretical, that it is action-guiding, and transcends history, culture, and individual and shared material conditions. In short, this model "sets itself the task of (largely reflective) construction, testing, and refinement of code-like theories that exhibit the core of properly moral knowledge" (p. 53). Walker argues that this form of moral consideration, when used by individuals in interpersonal situations, appears evasive, and when used in institutional or social contexts, appears bureaucratic or authoritarian. Although it is presented as impartial and objective, it "actually embodies a highly selective view appropriate to certain kinds of relationships and interactions in certain public, competitive, or institutional venues. These are traditionally contexts of male participation and authority, symbolically associated with the masculinity of men privileged by class and race as well as gender" (p. 53). The evaluations and judgments representing only a few are put forth; furthermore, and more damaging, "they uncritically reproduce the represented positions and locations as normative, i.e., as the central or standard (if not the only) case" (p. 54).

[10] This is in contrast to a Rawlsian conception of reflective equilibrium that offers "reasonably reliable agreement" or coherence between intuitive judgments about particular cases and those principles recognized as "the premises of their derivation" (Rawls, 1971, p. 20). Walker takes issue with the way in which intuitions, as raw

judgments among themselves. Moral *equilibrium* "is created through shared moral understandings and creates mutual intelligibility;" it is *reflective* to the extent that a community is "capable of making it and its conditions and consequences the subject of explicit attention and consideration" among members (p. 65). Walker, quoting Williams, describes transparency as a "hope for truthfulness" in society such that "the working of its ethical institutions should not depend on members of the community misunderstanding how they work" (1998, p. 72 quoting Williams, 1985, p. 101). Transparency is pursued within a democratic and participatory ethos, where the experiences and reflections of people with diverse points of view can be heard.

Moral reasoning is analogical and narrative in Walker's expressive-collaborative model; as such it allows for inductive thinking, open to new information; and is flexible rather than uniform. Narrative, for instance, helps determine responsibilities in the concrete by grasping previous histories of trust and expectation, and earlier applications of norms and values; "narrative constructions allow us to take thought backward in these ways, and then forward to explore the costs and consequences of moral choices for individuals and between them" (p. 69).

The way to get at morality's content is to track responsibilities, that is, morality is investigated as "socially embodied mediums of mutual understanding and negotiation between people over their responsibility for things open to human care and response" (p. 9). People come to know themselves and each other as "bearers of particular identities" and express their understandings through practices of

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data for theory and as negotiable assumptions, are accepted or pruned out by those who theorize ethics.

responsibility “in which they assign, accept, or deflect responsibilities for different things” (p. 9). These practices include, but are not limited to making evaluative judgments; “habits and practices of paying attention, imputing states of affairs to people’s latency, interpreting and redescribing human actions, visiting blame, offering excuses, inflicting punishment, making amends, refining and inhibiting the experience of expression of feelings, and responding in thought, act, and feeling to any of the foregoing” are also moral practices (p. 10). The skills on which these understandings are grounded are diverse: perception skills involve learning what to notice and how to attend to it; discursive skills require learning how to describe things and what it makes sense to say; and responding skills require learning how to appropriately take action in feeling and behavior.

The epistemic method of the expressive-collaborative model includes “a close description of and critical reflection on all such skills as belong to a particular form of moral life, the trainings that teach them, the kinds of human relations that make them possible, and the kinds of values and relationships they support in turn” (p. 66). The “epistemic rigging” of the theoretical-juridical model is less likely to occur in the expressive-collaborative model, argues Walker, because it is recognized that moral understandings are not only integrated with social understandings but are effected through social understandings. Similarly, different moral positions are constituted by social structure; such variables as the division of labor, different social situations and stations (of privilege, of subordination, of oppression, of marginalization), and hierarchies of power and status permit "different forms of moral self-description, define for them distinct ranges of accountability, and expose them to blame for different things or by different judges" (p. 17). Consequently, "not everyone is equally burdened or esteemed morally, and not everyone is in the same position to give or to demand moral account. Because social segmentation and hierarchical power-relations are the rule, rather than the exception, in human societies, the commonplace reality *is different moral identities in differentiated moral-social worlds*" (p. 17).

Walker (1998) argues that practices of responsibility arise out of and are reproduced in interpersonal relationships, in a continuing common life. Constructing and sustaining morality is a collaborative project, "constrained and made intelligible by a background of understandings about what people are supposed to do, expect, and understand" (p. 10). In order to see these moral understandings, we must look for them in reflective analysis, in critical reflection, and in normative reflection. We must engage in reflective analysis to "find out what moral norms are actually like, how they inhere in and are reproduced by interactions between people, and how moral orders are concretely embodied in social ones" (p. 9 – 10). Reflective analysis is informed by documentary, historical, psychological, ethnographic, and sociological investigations that attempt to give as complete a picture as possible of diverse human lives. Such an analysis can, for example, show how patterns of ascribing and deflecting responsibilities are socially shaped and reproduced, and how they might be construed differently. We must also engage in critical reflection about the nature of our understanding about practices of responsibility. This critical analysis will help us understand "who gets to do what to whom and who must do what for whom, as well as who has standing to give or to demand accounts" (p. 11). As such, it works toward transparency.

In addition to reflective and critical thought, Walker (1998) argues that reflection is normative "in that it holds particular moral relations and understandings (that are themselves normative) to some standards of shared intelligibility" (p. 12). Moral relations ought to be what they appear to be; to the extent that relations premised on human capacity for self-direction and grounded in mutually recognizable values are based on something different, such as deception or coercion, they are not moral interactions. Furthermore, the kinds of practices to which people are accountable ought to make sense to them. We must also engage in fully normative reflection, a task Walker understands as being comparative; "in other words, when we ask ourselves what can be said for some way of life, we are asking whether it is better or worse than some other way we know or imagine" (p. 13).[11]

Walker's (1998) understanding of responsibility as embedded in practices accords well with an ethic of care. In her account, selves are bearers of particular identities shaped by interactions and understandings that arise between and among people, not pre-formed identities that stand outside of time and history. Knowledge and practices of care, for instance, arise out of specific contexts in which it is recognized that moral understandings of our responsibilities are constructed by social understandings and social structure which are open to critical analysis and transparent reflection through analogical and narrative moral reasoning. As such, it stands in

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[11] Walker rejects the canonical Western project of defending a view about how human beings, transcending time and place, ought to live.

sharp contrast to notions of formal obligations to which autonomous people freely commit, and to underlying assumptions of distributive models of justice. Finally, Walker's understanding of responsibilities also require a democratic and participatory ethos where diverse points of view can be heard.

Deliberative Democracy: A Context in Which to Sort Out Needs and Responsibilities

Recalling that a public ethic of care requires that long-term care policies begin with a public discussion of needs, grounded in the experiences and perceptions of those giving and receiving care, and that these policies must be firmly grounded in a liberal, democratic, pluralistic society where moral responsibilities owed to each other can be determined, the resources of democratic deliberation are essential to a public ethic of care. Iris Young (2000) argues that "under ideal conditions of inclusive political equality and public reasonableness, democratic processes serve as the means of discovering and validating the most just policies" (p. 17). Democratic processes, as argued next, are also essential to discovering and validating policies that reflect an ethic of care, and which are integral to expanding care beyond the private sector.

While there are as many variants of deliberative democracy as theorists, at the heart of deliberative democracy is the idea that citizens and officials must justify any demands for collective action by giving reasons that can be accepted by those who are bound by action (Gutman and Thompson, 1996).[12] Deliberation promotes the legitimacy of collective decisions by making public the deliberations and the reasons

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[12] It is beyond the boundaries of this project to engage in a discussion of the variants of deliberative democracy. For substantive and important discussions of this subject, see, for instance, Benhabib (1996), Bohman and Rehg (1997), Calhoun (1992), Chambers (1996), Fishkin (1995).

for policy decisions in terms that citizens can accept, even if they disagree with them. Because people tend to be egocentric when arguing about issues, deliberation seeks to encourage a "public-spirited" perspective on public issues. Because we live in a pluralistic society with incompatible moral values, deliberation works toward promoting respectful decision-making, assisting participants to recognize moral merit in the views of those with whom they disagree. Because we have incomplete understandings of most moral conflicts, deliberation helps correct the mistakes that citizens and their representatives inevitably make. For those who are certain that their views are best, deliberation over time will tell. In short, deliberative democracy works toward transforming the preferences of citizens by orienting them away from private interest toward the public good, toward what Arendt (1954) calls an "enlarged mentality" (p. 241).

A model of deliberative democracy put forth by Young (2000) is particularly helpful for understanding how democratic processes can shape and inform a public ethic of care for long-term care. Young conceives of deliberative democracy as a form of public reason. As such, "[p]articipants in the democratic process offer proposals for how best to solve problems or meet legitimate needs, and so on, and they present arguments through which they aim to persuade others to accept their proposals... Participants arrive at a decision not by determining what preferences have greatest numerical support, but by determining which proposals the collective agrees are supported by the best reasons" (p. 23). Young also holds out hope that the deliberative process is transformational, that is, the preferences and beliefs one holds might be changed after listening carefully to others who are situated differently.[13]

Young's deliberative process is undergirded by several normative principles that shape and direct the relationships between deliberating parties. The principle of inclusion argues that decisions are legitimate "only if all those affected by it are included in the process of discussion and decision-making" (p. 23). The principle of political equality requires that those included in the deliberations should be included on equal terms; as non-dominated persons they "ought to have an equal right and effective opportunity to express interests and concerns" (p. 23).[14] The principle of reasonableness requires that those included in the deliberations have a set of dispositions that incline them to listen to others' ideas, that they are participants willing to work toward agreement, have an open mind, and are willing to change one's opinion based on what one hears. Finally, the principle of publicity requires that participants express themselves in ways that are accountable to those who listen.

It is to the principle of inclusion, particularly internal mechanisms of inclusion, that Young devotes most of her attention. Internal inclusion is concerned

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[13] Young's development of a deliberative model is in response to the shortcomings she perceives in aggregative models of democracy. The latter is problematic, says Young, because we take the preferences of individuals as given. No accounting occurs of how one arrives at preferences, of motivations, or a sense of being able to change one's mind. Also, given that democracy's task is to aggregate preferences in order to learn what people want, individuals need never leave the private realm and interact in public to reach some decision. Third, aggregative democracy is a "thin and individualistic form of rationality" (p. 20) and, fourth, there is no basis for normative evaluation of the substance of the results.

[14] Although Young explicitly articulates a norm of political equality at the outset, in the remainder of her book, she intentionally subsumes this principle within the principle of inclusion.

with the way in which people "lack effective opportunity to influence the thinking of others even then they have access to fora and procedures of decision-making" (p. 55). Exclusion occurs when only limited forms of political communication are allowed. Argument, with its emphases upon being articulate, dispassionate, and orderly in public debate, is the primary exclusionary mechanism. To counter this, Young argues that additional accounts of political communication are needed, not only to counter exclusion, but to also produce trust and respect, and move across structural and cultural differences. More complete accounts of political communication will include greetings or public acknowledgement, affirmative uses of rhetoric, and narrative and situated knowledge.

Greeting or public acknowledgement explicitly acknowledges others, with particularlity. Young (2000), working from Levinas, asserts that "greeting is this communicative moment of taking the risk of trusting in order to establish and maintain the bond of trust necessary to sustain a discussion about issues that face us together" (p. 58). Greeting announces the greeter as ready to listen while at the same time recognizing irreducible particularity to listen to and reason with a specific, unique individual. With such gestures of greeting, "discussion participants acknowledge that they are together with those they name, and that they are obliged to listen to their opinions and take them seriously. As a political issue of inclusion, recognition is primarily a starting-point for political interaction and contest, rather than its end." (p. 61). While it might be perfunctory or ritualized, without it, no discussion can occur at all because participants have not recognized each other as discussion partners.

Young's notion of affirmative uses of rhetoric suggests that deliberators ought to attend to, and not bracket, diverse forms of rhetoric. Deliberation based only on a "notion of non-rhetorical speech that is coolly and purely argumentative," assumed to be neutral reason, unsituated, and dispassionate, has, in fact, exclusionary implications (p. 64). Such expression "actually carries the rhetorical nuances of particular situated social positions and relations . . . many politicians, not to mention many academics and policy advisors, are very good at adopting a stance of controlled and measured expression of the neutral facts that commands authority just because it claims to be impartial and dispassionate, transcending the dirty world of interest and passion" (p. 63). Attending to rhetoric suggests paying attention to the emotional tone of what is said, the use of figures of speech, the forms of making a point beyond the use of speech (such as placards, demonstrations, or street theatre) and paying attention to the particularities of one's audience. An expanded conception and use of rhetoric can help get an issue on the agenda for deliberation, help construct and respond to particular and diverse constituencies, and motivate the move from reason to judgment.

When shared understandings in crucial respects are lacking, the affirmation and use of narrative and situated knowledge to make a point can help, suggests Young. A group suffering an injustice might not be able to frame their experience as an injustice, but they can tell stories that relate a sense of wrong. Reflection on stories develops a normative language that names a group's suffering and gives an account of why this kind of suffering is an injustice. Furthermore, narrative facilitates the development of a local public, people who come together on the basis of some affinity. Story-telling helps give voice to experience and becomes a way of politicizing situations, raising consciousness. Narrative also helps understand particular experiences of individuals in particular situations, sometimes challenges pre-understandings one has of people different from him or herself, and helps identify values, priorities, and cultural meanings that are important to people. Finally, narrative and situated knowledge from various social locations further the development of social knowledge that enlarges thought.

Young recognizes that there are dangers of manipulation, deception, and overgeneraliztion when political communication is broadened to include greeting, positive uses of rhetoric, and narrative and situated knowledge. To her critics, Young reminds that people can also be manipulated by argument. Furthermore, these practices are not meant to replace but to accompany argument. Greeting comes before the giving and hearing of reasons. Rhetoric accompanies argument, situating arguments for particular audiences with embodied style and tone. Narratives further understanding across differences when shared premises necessary for argument are missing. Finally, just as strong or weak arguments can be critiqued, so to can better and worse expressions of communication be critiqued. Effective expressions, however, should be thought of as virtues, says Young, not as litmus tests that decide whether one can participate in the deliberations.

Two other points about Young's model of deliberative democracy must be noted, although a complete accounting of these is not possible here. Contrary to some political theorists who argue that people must leave behind social differences, particular affiliations, and parochial loyalties, and instead appeal to the common good when they enter the public square, Young sees such difference as a political resource.[15] Social differences, while tied to culture, are best thought of as brought about by structural relations of gender, race, class, sexuality, and so forth. People positioned differently in social structures often have different experiences with and understandings of social relationships and the way in which society works. Their situated knowledge is essential in democratic processes; it increases the store of social knowledge such that citizens are more likely to make just and wise decisions mindful of structural inequalities and the processes by which these are produced and reproduced, and it moves participants beyond narrow self-interests to a concern for justice. Inclusion here argues that we ought not mean "simply the formal and abstract equality of all members of the polity as citizens. It means explicitly acknowledging social differentiations and divisions and encouraging differently situated groups to give voice to their needs, interests, and perspectives on the society in ways that meet conditions of reasonableness and publicity" (p. 119).

Also contrary to the views of some political theorists who reject representation as being compatible with authentic democracy, Young argues that "under normative ideals of communicative democracy, representative institutions do not stand opposed to citizen participation, but require such participation to function well" (2000, p. 125).[16] Representation that includes and encourages the perspectives of marginalized and disenfranchised groups, and multiple fora and institutional

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[15] See Chapter Three for an extended discussion by Young (2000) of those who suggest that differences be left behind in the public square.

[16] See Young (2000), Chapter Three for an extended discussion by Young of her critics of representation.

contexts to which citizens are invited to speak and listen can deepen democracy and extend itself beyond face-to-face encounters to large-scale democracies.

Furthermore, the variety of activities subsumed under the label of civil society create important venues for participation and expressions of structurally situated perspectives. The level of associational life in civil society that Young calls political associations are best suited for public deliberations.[17] Here, citizens "self-consciously focus on claims about what the social collective ought to do" (p. 162). Questions of what issues ought we be debating, what principles and priorities should guide public life, what policies should be adopted, and what citizenship entails can be brought to the foreground, with an aim (often) to influence policy development or economic practices. The functions of the public sphere, according to Young, include creating a mechanism by which people are connected to power. Opportunities to expose and oppose arbitrary use of power and influence public policy are fashioned. Finally, public spheres can foster social change projects without directly targeting the state or markets. Discussions about different ways of doing things can lead to alternative norms and practices; to the extent that these alternatives seem better for society or some group if adopted, public spheres can cultivate new ideas and practices.[18, 19]

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[17] Young distinguishes three levels of associational life. Besides political associations, private associations such as clubs, family gatherings, private parties, or religious gatherings are often exclusionary and bring joy and meaning to human life. Civic associations engage in outward-focused activities by members to contribute to the good of society. These two levels of associational life have self-organizing activities, that is, their interests and experiences help each other develop their "social voices" (p. 164) and bring together disenfranchised people who can improve their lives "through mutual aid and articulation of group consciousness" (p. 165).

[18] Young points to changes brought about by contemporary feminist movements and environmental movements as examples of "changing society through society" (p. 178).

Deliberative Democracy and Oregon

With Young's ideal conception of deliberative democracy as background, we can review Oregon's attempt to provide universal access to health care for Oregonians. Understanding Oregon's experience is important to the project of defining and identifying needs of and responsibilities for frail elders because it provides a window through which to assess the limitations and strengths of democratic deliberation in action.

The Oregon Basic Health Services Act was enacted in 1989 and designed to decrease the state's 18 percent uninsurance rate (in 1990) in three ways: create a high risk purchasing pool to provide access to private insurance for persons with pre-existing medical conditions; require employers who do not provide insurance for their employees to do so or contribute to a state insurance fund that would purchase coverage for uninsured workers; and expand Medicaid to all persons with incomes

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[19] Young's conception of the deliberative process also accords well with Walker's understanding of practices of responsibility. For instance, Walker's sorting out of moral responsibilities requires a democratic and participatory context. Negotiations in which participants discuss and harmonize judgments between and among themselves about what responsibilities they hold to each other is a process akin to Young's argument that decisions be made not by determining preferences based on numerical support but by determining which proposals participants believe are supported by the best reasons. Young's normative principles that shape and direct the relationships between deliberating parties - - inclusion, political equality, reasonableness, and publicity - - are reflected in Walker's discussion of moral responsibility as a collaborative community project of tracking responsibilities in which the experiences of all members are important to understand. Such experiences are mediated by various dimensions of social structure, as both Young and Walker recognize, and to avoid Walker's epistemic rigging of moral responsibilities by the powerful and elite, diverse constituencies must be included in the discussion. Walker's emphasis on analogical and narrative reasoning accords well with Young's argument for expanded forms of political communication that include affirmative use of rhetoric and the use of narrative and situated knowledge to reach understanding across diverse experiences and locations.

below the federal poverty line.[20] To accomplish the latter, rationing of health care was required such that high-cost, low-yield interventions could be traded for a basic level of care likely to result in mortality and morbidity outcomes on a par with other industrialized countries.[21] This third strategy has been most controversial.[22]

The Act also created an Oregon Health Services Commission (OHSC) to establish priorities among health services for Medicaid recipients such that low-priority services, rather than people, be cut from coverage when reducing expenditures was necessary. The commission was to complete a technical analysis that merged cost-benefits and health outcomes research with a process for public participation to determine community values about health care. The commission was to base its priorities on the widest possible hearings from the communities most affected. Senate Bill 27 emphasized:

> The commission shall solicit testimony and information from advocates for seniors; handicapped persons; mental health services consumers; low income Oregonians; and providers of health care, including but not limited to physicians licensed to practice medicine, dentists, oral surgeons, chiropractors, naturopaths, hospitals, clinics, pharmacists, nurses, and allied

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[20] The highrisk purchasing pool plan currently covers about about 4,000 Oregonians. The employer mandated insurance provision has not yet been enacted. To enact this, an ERISA exemption needed to be secured by January 1, 1996. Sadly, this was not accomplished and this failure leaves a large gap in Oregon's health insurance safety net.

[21] Prior to the Act, Oregon's Medicaid eligibility was set at 57 percent of the poverty level. No other state funded Medicaid at the 100 percent level. For Oregon to do this, it required adding 77,000 people to the pool of covered persons at the time the act was implemented (Bodenheimer, 1997).

[22] This summary of the Act comes from Senate Bills 27, 534, 935. 65th Oregon Legislative Assembly. 1989 regular session.

health professions (Oregon Legislative Assembly; Senate Bill 27, section 4a, codified under ORS 414.036).

The Act embodied several principles: a social obligation exists to guarantee universal access to a basic level of health care; necessary or reasonable limits on resources mean that not every beneficial service can be included in a basic level of health care; and a public process that also includes considering social values is required to determine what services will be included in the basic level of health care (Kitzhaber, 1990). Commitment to defining and accessing basic health care, and the distribution of health care through an open and fair process became benchmark themes for the work of Oregon citizens.[23] After the establishment of the Act, and before the first prioritization report was due on March 1, 1990, the newly formed OHSC began to "actively solicit public involvement . . . to build a consensus on the values to be used to guide health resource allocation decisions" (Pinkerson, 1992, p. 161). As such, the organizers were determined to counter the criticism already

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[23] It should be noted, however, that Oregon's commitment to this process did not begin with the Oregon Basic Health Services Act. The Oregon story in terms of health care and Medicaid is a long and complex one, dating to the early 1980s. In 1982, the Oregon Health Decisions movement, a citizen-based grass-roots effort to put in place the mechanisms by which health care policy should be set for and by the citizens, was begun by Ralph Cranshaw, a psychiatrist, and Michael Garland, a theologically trained ethicist. Following the Governor's Conference on Health Care for the Medically Poor in 1982, in which the two men presented their concept of a citizens-based, democratic ranking and prioritization of all public goods and services, an ambitious project of engaging citizens throughout the state began. Over 5000 citizens, meeting in a variety of sites designed intentionally by the OHD staff to draw diverse groups to accessible sites, discussed, initially, how rationing could be explicit and in keeping with community values. Subsequent discussions through the years focused on other related topics such as care of the dying. By 1985 and 1986, the OHD movement had attracted national attention. Although other players came on board, the OHD remained a critical and guiding force in subsequent policy decisions (Cranshaw, Garland, and Hines, 1990; Hines, 1986).

present that the middle-class was rationing health services to the poor. Activist groups and media venues urged citizens to attend town meetings; all Medicaid recipients received notice of the nearest meeting place. Initially, twelve community forums were held and attended by 1500 people. Later, another 47 meetings were held, attended by 1,048 citizens. The goal of these meetings, according to Garland,

> . . . was to generate for the HSC publicly examined statements about what makes health care "important to us" as a common good. Participants were asked to think and express themselves in the first person plural, namely as members of a statewide community for whom health care has a shared value. They were not asked to think hypothetically about what might make health care important to some other group, but to think concretely and discuss among themselves what makes health care an important aspect of the common good of the community in which they live and to which they feel themselves morally bound (1992, p. 71).

The prioritized list that eventually emerged from this process for the March 1990 report was long (over 1600 treatment pairs), detailed, complex, and incomplete. The final list, given to the legislature in June 1991, contained 709 treatment pairs. The legislature drew the line at item 587. Although the benefit package was surprisingly substantive, covering then current Medicaid mandates as well as many services not previously covered, national outcry greeted the final list because of its rationing. Yet it went forward; in spite of being denied the needed waiver to implement changes in Medicaid under Bush, the plan was approved by the Clinton administration in 1993. On February 1, 1994, the Oregon Health Plan went into operation.

In assessing the Oregon plan, many criticisms have been levied against it.[24] Some believed that rationing was unnecessary, given seemingly large federal surpluses that were used to rescue the savings and loan industry or subsidize tobacco farmers. Others noted that rationing would be unnecessary if current "waste" in the health care system, such as dollars spent on overpriced and/or low-benefit treatments, were cut (Relman and Levinsky, 1990). Economist Joshua Wiener found it "troubling to ration medically effective procedures before we have truly exhausted other routes to cost containment" (1992, p. 110).

Others objected to a plan that rationed the health care of the poor on the basis of middle-class perceptions (Rothman, 1992). Charles Dougherty argued that the plan ignored Catholic liberation theology's preferential option for the poor, warning that social solidarity would be lost as "we" drew lines around what "they" might receive (1990). He also, reflecting the concerns of many others, cast doubt about the ability of middle-class citizens to move beyond race and ethnicity, already high correlates of chronic and acute disease and Medicaid status, in their decision-making for the services that would be included (Dougherty,1991); an inability to move beyond race and ethnicity would result in increased inequality. Relatedly, some argued that the harshest burdens of the plan would fall on AFDC mothers and children - - the least powerful and most needy - - while other, more "worthy" needy,

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[24] My intent is not to develop or respond to all of these criticisms, but rather note them as part of a larger context of connecting Oregon's experiences with deliberative democracy and its potential usefulness for long-term care.

such as the elderly and disabled, were protected (Friedman, 1991; Rothman, 1992). Sara Rosenbaum of the Children's Defense Fund argued that " 'Prioritization' is reserved for the weakest and poorest state residents - - women and children living at less than half the federal poverty level and utterly dependent on direct state assistance" (1992, p. 103). In short, the two-tiered nature of the system in which the needs of the poor were decided by the middle-class would further reinforce an immoral system, making it more difficult to transform deeper injustices (Dougherty, 1992; Menzel, 1992; Winslow, 1989).

Additional criticisms included the fact that neither providers or taxpayers were affected by this system; no one questioned the fee structure of physicians or CEOs, the profit margin of the health care industry, or why taxpaying citizens should not pay more taxes (Capron, 1992; Matthiessen; 1992). Some critics argued against the utilitarian premise of the project that aggregated the good of health care for all those who fall below the poverty, while at the same time creating the potential that some current Medicaid recipients will be worse off (Winslow, 1989). Attempts at prioritization based on aspects of quality-of-life and cost-benefits were problematic for some, particularly when external judgments were used to determine the quality of life in certain disease states based on judgments by people not currently experiencing such states (Dougherty, 1992; Hadorn, 1992). Steinbrook and Lo (1992) argued that there was no guaranteed floor of basic benefits set for the legislature below which they could not go in making their determination point on the prioritized list of treatment pairs. They noted that "[b]ecause the line is financial, not medical, the level of coverage can rise and fall with budgetary pressure" (p. 343). Finally, some critics noted that in spite of best intentions, the process of deliberation was exclusionary. Meetings were held in middle-class forums, led by middle-class people, who used privileged discourse of arguments and principles. Two-thirds of the attendees were health care providers, two-thirds were college graduates, and while consumer organizations representing Medicaid recipients were involved in the process, only 5 percent of attendees were Medicaid recipients. Children were not included, and it is questionable how many AFDC mothers would be comfortable speaking out in such venues (Menzel, 1992).

In spite of these criticisms, the Oregon Health Plan has gained a modicum of respect and acceptance, at least among Oregonians. Since the Oregon Plan went into operation in 1994, the prioritized list has been modified every two years in conjunction with Oregon's biennial legislative session. Although the line of inclusion in the benefits plan has been moved to item 574, the package is more comprehensive than many traditional commercial health benefit plans, and traditional Medicaid plans of other states (Rutledge, 1997). Client satisfaction surveys indicate that satisfaction with the health care plan, client perception of health status, and satisfaction with access has increased since implementation in 1994 (Leichter, 1999). The number of appeals submitted by OHP recipients (between 40 and 80 appeals per year from 362,000 patient encounters for service) is judged low (Leichter, 1999). Since the Oregon Health Plan went into operation in 1994, "more than 100,000 people have been added to the Medicaid program, and it is politically popular. Serious complaints about the prioritized list are hard to find. Major problems exist, but they mirror the difficulties of the health care system around the nation" (Bodenheimer, 1997, p. 651).

Leichter (1999) suggests that in the long run, one of the plan's most important accomplishments, given that it created a "politically accountable, credible, and fiscally responsible program," is that it has set the stage for expanding public and private access to health care.[25] Similarly, Jacobs, Marmor, and Oberlander (1999) note that the success of Oregon's innovation is more political than technical.[26] The discourse of rationing made public the private rationing decisions made daily that limited care to the underinsured or uninsured. This discussion "reconfigured debate toward openly acknowledging, as a society, what medical services Amerians - - even the politically eviscerated poor - - should receive or go without" (1999, p. 177).

Even though the outcome of Oregon's Medicaid experiment, as judged by increased access to health care for the poor and a substantive benefit package, is successful, some of the criticisms levied against the process cannot be easily dismissed, particularly if the idea of democratic deliberation is held forth as a mechanism by which to prioritize the long-term care needs of the elderly. Although the criticisms against Oregon are severe, and many are legitimate, such criticisms have also received thoughtful rebuttals. In particular, two criticisms of the Oregon deliberations are important to address if Oregon's experiences are to do any practical

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[25] As evidence of this, Leichter points to the 1996 voter-approved ballot measure to increase the state's cigarette tax from 36 to 68 cents per pack with additional revenues targeted toward expansion of the Medicaid program to include women and children with incomes up to 150 percent of the federal poverty level, and creation of the Family Health Insurance Assistance Program for uninsured working Oregonians. Both policy initiatives enjoyed strong bi-partisan support in the state House (52 to 2) and in the Senate (26 to 0).

[26] In fact, as a technical undertaking, the rationing among Medicaid recipients did not result in the expected savings for expansion. Jacobs et al. (1999) conclude that expansion occurred though funding via familiar efforts: raising revenues directly and negotiating contracts with providers.

work for using the deliberative process to define and prioritize the issue of needs in long term care.

One of the most serious criticisms that cannot be easily dismissed of what Oregon did is that it legitimated and reinforced a two-tier health care system. In doing so, an implicit message was sent to the poor that their lives are less worthy than the lives of middle-class Oregon citizens and they are relegated to second-class citizenship status. Furthermore, given the piecemeal approach of Oregon's plan where only the poor were subject to rationing, and given what many will define as successful outcomes in the Oregon Medicaid experiment, the political will to push for universal access to health care may well have been quashed. As Daniels (1985) suggests, isolated proposals will make it more difficult to correct deeper injustices in our health care system.

Leonard Fleck has responded to these sorts of criticisms by defending Oregon's actions from a framework of "non-ideal justice" (1990).[27] Using the concepts of a problem/decision sphere and moral meliorism, Oregon's actions were "just enough."[28] Given the considerable turnover in the Medicaid population

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[27] See Fleck (1987) for a detailed description and moral defense of this framework.

[28] A problem/decision sphere is "defined by what is manageable in the way of solving a problem and effecting change, given a host of political, economic, organizational, normative, and technological constraints, peculiar to that problem"(p. 207). The 400,000 Oregonians without health insurance, the heterogeneity of reasons for not having insurance, the rising costs of the Medicaid program, and its relationship to the federal government were all factors that came together such that the most that could be hoped for would be patchwork reform. Even though piecemeal reforms are neither fair nor rational, practically speaking for the moment, they might be all that can be considered. Moral meliorism is the notion that something morally commendable has been done if, "in our problem/decision sphere, we can bring about a more just state of affairs, all things considered, than what existed previously, even though this improved state of affairs will still fall short of what an idealized conception of justice might

(estimated at 25 to 35 percent per year) that leaves former Medicaid recipients likely to be uninsured in low-paying jobs, and the low probability that one would need an organ transplant (much less find a suitable match), Fleck argues that the poor themselves would likely define for themselves that the new plan is in their best interest. Therefore, the requirements of moral meliorism have been met.[29] And while the Medicaid program at the federal level is seriously flawed from a justice perspective, the Oregon legislature did perhaps the best they could for the time within their problem/decision sphere.

The Oregon plan has also been severely criticized for its exclusionary process in coming to understand community values. As noted earlier, in spite of its best efforts, representation at town hall meetings by Medicaid beneficiaries was estimated at five percent of attendees. Clearly this is unacceptable if the outcomes of deliberations are to be legitimate. Perhaps this criticism can be tempered, however, by realizing that in retrospect, current Medicaid recipients report increased satisfaction with access (70 to 88 percent from 1994 to 1996), care (increase from 77 to 84 percent from 1994 to 1996), and health status (66 to 76 percent from 1994 to 1996) (Jacobs, Marmor, and Oberlander,1999; Leichter, 1999). It may be that those advocating for Medicaid beneficiaries at the town meetings did a better job than recognized at representing the perspectives of their constituency.[30] This criticism can

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require" (p. 209). This concept provides a reference point to measure in the concrete whether a more just state of affairs has been furthered in a non-ideal world.

[29] In response to the criticism that Oregon's plan perpetuates a two-tier system of health care, Fleck reminds readers that the Oregon proposal makes explicit and visible the two-tier/multi-tier system that has long been operational.

[30] I use the word "perspectives" intentionally here, following Young's (2000) understanding of it as something that does not contain specific content (as an interest

also be tempered by recognizing that while the OHSC made serious omissions in their attempt to be inclusive, we can learn from Oregon's failures about what to do differently in future deliberations. Young's notion of inclusive deliberative democracy, for instance, requires that the Young's deliberative process be developed from and guided by normative principles of inclusion, of political equality as non-dominated persons, of reasonableness, and publicity. An openness to forms of communication other than argument, for instance, may well have invited Medicaid recipients not only to the table but to the table as discussion partners. Being invited to tell one's story is very different than being asked to defend a point of view to others differently situated than oneself. Closer attention to venues in which to meet, forms of communication other than speech, and speech acts other than argument may well have made the process more inclusive.

Deliberative Democracy and a Public Ethic of Care

Before moving to a discussion of how deliberative democracy can be useful to a discussion of needs in long term care, it is important to consider its congruency with a public ethic of care. Determining what needs count as legitimate and how such needs will be met is a matter of justice, and deliberative democracy is increasingly seen by holders of various perspectives of justice as useful to the task of sorting out many political matters of justice (Emmanuel, 1996). Be that as it may, such a process should not be at odds with a public ethic of care, nor is it. In fact, the dialogical and

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or opinion might); rather it arises out of one's social position and is a way of looking at social processes without determining what one sees. In doing so, perspective promotes certain starting points for discussion. In and of itself, perspective is not illegitimate in the way an interest or belief might be.

communal method of deliberative democracy maps well with the assumptions of an ethic of care and is necessary to moving an ethic of care out of the private sector into the public.

Deliberative democracy is congruent with the assumptions of an ethic of care for several reasons. First, the process of democratic deliberation builds from and is reflective of the notion of a socially constructed and relational self, in contrast to a detached, atomist self with a pre-determined identity. The public sphere is seen as a meeting ground:

> . . . where people shape identities through action and interaction, through the exchange of narratives and opinion, through deliberations and debate, and where, in so doing, they can continually revise and transcend their images of 'self' and 'other.' Here identity depends more on what you do than on what you are. Rather than being fixed, it remains open to change (Sevenhuisjen, 1998, p. 14).

Here in the public square the development of identities and consciences, that is, our understanding of what constitutes a good act, happens relationally. This is not strictly an interior process that occurs when one reflects on the effect of an action on the self, but instead is a process that requires the presence of the other. In the public square, individual selves must struggle with the difficult problem of the effect our choices have on tangible, identified others. As we struggle communally, we solidify, question, revise, and/or reject our previously held commitments (Young, 2000).

Second, deliberative democracy is congruent with an ethic of care because it creates a public space in which we can meet the "naked face of the other" (Levinas in

Hendley, 1996). Attentively meeting the needs of concrete, individual, embodied persons is necessary to the practice of care, to caring about the other. Because we lack consensus on the goals of health and social care for the frail elderly, because our need for care is infinitely expansive, and because we cannot meet all needs given limited resources, some needs will not be met. Thus, while a just way is required to prioritize needs and determine which needs will be met through public coffers, such a process must, for the care proponent, also hold in high esteem the needs of the concrete other. Any emerging plan, says Zoloth (1999), must begin with face-to-face encounters: "The selective survey will not do; the advice of many experts will not be enough. One needs the radical recognition that what one chooses for the body of another will happen also to one's own body; it is the physicality and the *dbq* character of the encounter.[31] The encounter must be insisted upon" (p. 227).

This holding of the other in high esteem is precisely what occurred in Oregon with its health care reform. As an example of democratic deliberation, citizens around the state debated in small groups what priority health care should have in relationship to other social goods, what general allocations should be set within health care budgets, and what care should be provided under Medicaid. Zoloth (1999) comments that:

> [i]t was precisely this face-to-face encounter that made the discussion so compelling. Rather than listening to an abstract dialogue among political leaders and faceless aides about health care policy, group participants were invited to form a moral community, to describe to their neighbors their fears

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[31] *Dbq* is the Hebrew word for "cleave."

> and desires about their embodied self, their flesh, and their vulnerable, fragile lives. Asking questions about what to value about this embodied life created a shared text, a terrain that needed its own language for negotiation and trade. For making trade-offs requires the language of the shared public space. This process brought into public the most private of all intimacies – sexuality, birth, and death (p. 32).

Those who supported the Oregon plan supported it, in part, because of its commitment to strong democracy and public discourse. Particularly in discussions of health care allocation and prioritization, where questions turned on embodied selves, "it was the encounter with the actual face of the other in direct dialogue that was crucial and unique about this work. . . . The process enabled us truly to face the other in ethical encounter" (Zoloth, 1999, p. 69).[32]

Not only did the deliberative process in Oregon allow participants to engage in concrete face-to-face encounters with the other, it expanded the participants' awareness of themselves as socially and historically belonging to a particular community to which they were responsible and which, in turn, was responsible to them (Walker, 1998). Thus the shape of the discussion was broader than finding a series of rule or principles that could be applied to clear-cut moral tensions

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[32] Young (2000) challenges the notion that a face-to-face encounter is necessary in the deliberative process. While we need freedom to associate and meet in small groups to discuss mutual concerns, we must also respond to large-scale politics that link millions of people in myriad ways. Hence we need a process of representation, and a conception of politics and society as decentered. The deliberative conversation, rather than having a defined beginning and end, takes place over time, in a multitude of contexts and across wide distances. While the face-to-face encounter is not at odds with Young's framework of deliberative democracy, to limit it to this is too restrictive.

(Sevenhuisjen, 1998); rather the discussion extended to the conflicts participants faced in their responsibilities to each other, and the effects of one person's actions upon the other. As well, the location of the discussion was the "here-and-now" rather than a depersonalized context in which neutrality, rationality, abstractions, and impartiality guided the search for a normative frame in identifying and prioritizing human rights. The deliberative process "put forth a vision of citizenship that involved some sacrifice and a voluntary acceptance of the other at your side who must share the commons with you" (Zoloth, 1999, p. 72). Such a process is surely in sync with an ethic of care's assertions that people are grounded in concrete and interdependent relationships with others, and that with attentiveness and responsibility, we can respectfully and carefully consider caring practices amidst scarcity of resources.

Finally, democratic deliberation is congruent with a public ethic of care because public deliberation provides a context in which private concerns can become public issues. This too happened in Oregon. The small group process, in addition to discussing the question of need, elected representatives to serve as delegates at a health care parliament. Here the delegates would represent the group's consensus and help author a list of community values about health care that would be promoted in and circulated around the state as a moral vision of health care. Subsequently, "the group was not only a moral community; it was a democratic community of civic discourse. It is this combination of intimacy, acknowledgment of desire, and democracy that created validity for the process and the parliament (Zoloth, 1999, p. 33).

The moving of care from the private to the public sphere is important to an ethic of care for at least two reasons. First, an ethic of care requires that moral agents be firmly grounded in concrete situations (and not abstracted from them). The ideals of democratic deliberation require that those in public conversation in the public square are those who are affected by and have a stake in whatever issue is on the table. Thus democratic deliberation provides a context in which grounded moral agents can do their work, and because members of the deliberative process are people closest to whatever issue is on the table, they are less liable to commit, recalling Tronto, "privileged irresponsibility." With the inclusion of those in the public square whose lives are shaped by the issue at hand, the gulf will be lessened between those who care about and care for (typically those with power and privilege) and those who do the work of care and receive care.

Providing a context in which private concerns can become public in democratic deliberation is also important because it is only in this way that a feminine ethic of care can be transformed into a feminist ethic of care. Democratic deliberation brings to the public square those issues that have traditionally been assigned to the private sphere and the work that has traditionally been assigned to women. By bringing care to the public square, we bring to the foreground issues and concerns historically dismissed or overlooked. Those most affected by the giving and receiving of long – term care, for instance, will bring different, and perhaps competing, priorities to the table. These differences will enable participants to discuss care publicly where deliberation about the best way to care and the social arrangements to care well can occur. Such conversation can also lead to discussions about human identity and nature, challenging the notion the ideal citizen is a self-sufficient citizen with a health body and no need of care.

Finally, such conversation can even transform our understanding of citizens as extending beyond wage earners to all people. In doing so, the political context is shaped, bringing the virtue and practice of care to a more central location in making political judgments. This in turn will shape how well we are able to care for each other. Sevenhuijsen puts it this way:

> It is my contention that we can develop such a vision only by situating the ethics of care in ideas and practices of democratic citizenship. Its ideas about attentiveness, responsiveness and responsibility can have a transformative effect on how we proceed in processes of political judgment and give us a better understanding of the way in which human needs and well-being are treated in politics" (Sevenhuijsen, 1998, p. 66).

When care is recognized as a basis for political practice, it can inform our practices as citizens (Tronto, 1994). It will direct us to a public discussion of needs in which attentiveness opens our eyes to groups whose needs for care have not been met, making such neglect a public issue worthy of debate. It will direct our moral sensibilities to organizations and institutions that have not been responsible in meeting the needs of those it claims to care for. It will move the work of care givers and the experiences of care receivers to a place where their knowledge and understanding can serve as a basis for public policy.

Deliberative Democracy and Long-Term Care

With Young's model of deliberative democracy as a framework, and lessons learned from Oregon's experiences with prioritization of health care needs and discussions of responsibilities, we can begin to envision how the deliberative process can be useful to building a system of long-term care grounded first and foremost in meeting the needs of frail elders for long-term care and attentive to practices of responsibility.

Young's normative principle of inclusion requires that those who will be affected by the outcomes of the decision be included in the process of discussion and decision-making. Most immediately this includes current Medicare beneficiaries and elderly Medicaid beneficiaries; in short, a population mostly defined by being aged 65 and older. It will also include those likely to serve as informal care-givers, if the need for long-term care becomes a reality. It might well include future cohorts of elders such as the "baby boomers" who may at some point be in need of giving and/or receiving long-term care. Furthermore, it must include those who set elder care policy, direct health and social agencies providing services for elders, and a variety of professionals and para-professionals who perform various tasks related to health and social care.

Young's norm of political equality requires that this large group of deliberators must do their work as non-dominated persons who have equal rights and opportunities to be heard. Consequently, the same kind of careful attention given to what a state legislator or HCFA representative presents must also be given to the cognitively intact but frail 85 year-old institutionalized African American woman receiving Medicaid. Similarly, the exhausted and bitter daughter of an elderly parent with Alzheimer's disease deserves the same attentive discussion partners as the well-known and respected geriatrician.

Young's norm of reasonableness means that deliberators enter the discussion as both givers and hearers of reasons, that they express a willingness to work toward agreement, and are willing to be influenced by what they hear. It does not mean, however, that the deliberators bracket their differences to avoid conflict and promote order. Rather, these differences are used as resources to understand a full range of visions and concerns about the best kind of long-term care for elders. It is to be expected that the concerns of the overwhelmed care-giver, the institutionalized poor person, or the expert physician or policy maker bring to the table will be diverse, mediated by gender, by class, by race and ethnicity, and by personal values and beliefs. While consensus would be ideal, "conflict and disagreement are the usual state of affairs" (Young, 2000, p. 43).

Young's norm of publicity requires that the deliberations occur in an assortment of venues, all of which are open and transparent in their dealings. Certainly public hearings and town hall meetings will be important as they were in Oregon. Discussions in city halls, in state and federal legislatures, and in the courts are instances of Young's concern for deliberation in politics and society as decentered. But Young would also argue for deliberations to occur in settings most comfortable and familiar to care-givers and care-receivers: in nursing homes where the arrangements of the physical environment and attending sights and smells of medically-modeled institutions cannot be ignored; in homes where medical appliances and equipment have overwhelmed common living space; in senior centers and adult day care centers located within the center-city, the suburbs, and in rural areas; in assisted living centers; with home-bound seniors who receive "meals-on-wheels;" in care-giver support and education groups; and in homes and group homes where hospice services are delivered. Given that aging is more than decline and disability, discussions with healthy elders in settings representative of their interests and leisure would also be important for a thick description of inclusiveness.

Furthermore, publicity requires that "expression aims in its form and content to be understandable and acceptable" (Young, 2000, p. 25). This implies some of what has already been suggested, specifically that the strangers who come together will treat each other with respect and express themselves in ways that are accountable to those who listen. It also allows that expanded forms of communication be used. The overwhelmed care-giver or institutionalized and poor elder may have little in common with expert policy or health care practitioners by way of shared premises on which to argue, and it may require enormous effort, for instance, for policy practitioners accustomed to the crisp and concise language of bureaucratic and technocratic colleagues to engage with the narrative told by an old woman. It may require even more effort for such experts, even if not engaged in direct deliberations with care-givers and care-receivers, to accept the insights of laypersons as legitimate knowledge from which to build public policy for long-term care. Likewise, the preoccupation that often accompanies the hard work of care-giving and care-receiving can cause individuals so situated to lose sight of the larger process - - that others too have pressing care needs, that likely not all needs defined as needs for care can be met, and that difficult and painful decisions need to be made communally.

This process of deliberation among differently situated participants in diverse settings is not valued for its efficiency. The deliberative process in Oregon that resulted in the Oregon Health Plan spanned a decade. Deliberation done as described above about what kind of long-term care system best meets the needs of frail elders may well take just as long and longer. Even then, consensus might not be reached. However, consensus is not the only indicator of success of the deliberative process; increased ability to understand the perspective of someone situated differently than oneself and a willingness to recognize the perspective of another as legitimate and worthy of attention is also important. As noted earlier, deliberations that reflect all social experience promote the epistemic conditions needed for creating just and caring policies (Young, 2000).

Content of the Deliberations

What is it that participants committed to developing a long-term care system congruent with a public ethic of care will deliberate? This question, of course, already narrows the field of possible discussion topics. Deliberators could, for instance, begin with larger questions about social and health care justice. We could, following Norman Daniels, deliberate about the kind of health care system that would arrange and distribute health care so as to allow individuals to achieve a fair share of the normal range of opportunities present in society so that one can complete one's life plans (1985). Or, following Daniels's attempts to address questions on intergenerational justice and health and social care, we could ask, "How would rational agents design institutions to prudently allocate fair shares of basic social goods over their lifespan?" (1988, p. 66). Questions about health care as a right, about universal access to health care, about what kinds of health and social care are basic to human well-being, and the priority health care should hold relative to other health and social goods at large are critically important moral questions. They are also beyond the scope of this project. One might object, however, that these sorts of questions must be addressed before focusing more narrowly on questions about long-term care. In a perfect world, this would be preferred. In countries where strong welfare states are already established, in contrast to the "reluctant welfare state" of the United States, this would perhaps be more possible. For the present, however, those of us who care deeply about matters of universal access to health care from "womb to tomb" must continue with persistence and wisdom in pursuing this. We must also be pragmatic.

The framework of non-ideal justice allows us to focus our attention on the sub-population of older adults. Given that Medicare and Social Security are almost universal in their coverage for older adults, these policies carve out a section of political, social, and economic life that approximate a problem/decision sphere where solving problems and effecting change, while nevertheless difficult, is imaginable.[33] Within this decision sphere, it is possible to work toward concrete changes that will

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[33] Changes here are certainly more imaginable than in our health care system at large, given that the latter appears nowhere on the federal agenda at the moment, and has not been present since the reforms initiated by the Clinton administration failed early in his administration.

bring about an improved state of affairs for the frail elderly, even if these changes still fall short of what is required for all.[34] Stated differently, we can pursue a revised long-term care system for the elderly informed by a public ethic of care within our already defined problem and decision sphere. In doing so, we can improve long-term care for the elderly, recognizing that we have not yet addressed, much less implemented, the resources of a public ethic of care in other arenas.

The questions posed to deliberators, at least initially, should be vision-type questions. What are the goals of health and social care for the elderly and for the frail elderly? Perhaps we hope to extend life at all costs; perhaps "quality of life" concerns enter in at some point. What makes long-term care important to us and what is it we want long-term care to provide for us? Perhaps we hope that such care will restore us to an earlier level of health; perhaps we hope that it will slow down the decline brought about by illness and disease or help us adjust to it. Perhaps we hope that such care will ensure our safety and allow also for independence, and promote a way for us to sustain relationships with loved ones and avoid boredom and loneliness. What priority should long-term care hold relative to other health and social goods needed by the elderly? If we design a Mercedes long-term care system within our allocated budget, we may well leave unfunded other important social goods that elders find give their lives meaning.

With some understanding of how deliberators respond to these large questions, further deliberation can occur regarding what counts as a need in long-term

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[34] This assumes, of course, that the deliberation within the defined problem/solution sphere is bounded by Young's principles of inclusion, political equality, reasonableness, and publicity.

care. If we value extending life at all costs, then budgeting $30 billion dollars a year on Left Ventricular Assist Devices may well be defined as a need within long-term care. If we value long-term care for its potential to slow down the process of disease and decline, and/or help us adjust to diminished functional abilities, then such services as rehabilitation, routine physical examinations, foot and dental care, prescription drug coverage, and assistive devices for sensory impairments might well be defined as needs. If long-term care is valued for its potential to preserve relationships with family members, then services that support family care-givers and prevent their emotional and physical decline - - such as homemaker and chore workers or home health aides for personal care - - may be constructed as needs. If long-term care is valued for its potential to affirm human dignity even in the midst of great vulnerability, then such persons as nurse aides and social workers, evaluated by their ability to attentively respond to individuals and compensated with a living wage, are necessary.

With some understanding of how needs for long-term care are defined, more technical discussions can occur. How should our emerging system of long-term care be financed? How should long-term care services to frail elders be made available and delivered? What should be the relationship between acute health care and long-term care in our systems of care and funding mechanisms? These are not simply technical questions requiring technical fixes but are undergirded by certain moral, social, and political assumptions and have the same kinds of implications. From a public ethic of care, for instance, we need to ask which kinds of funding mechanisms are congruent with the assumptions of an ethic of care. What kinds of public and institutional long-term care policies are likely to affirm an ethic of care? What kinds of political, economic, and social structures affirm or preclude the possibility of a public ethic of care. Although these questions have technical dimensions best worked out by system experts (such as the pairing of diagnoses with treatment by health care experts in Oregon), democratic practices can precede system solutions.

The discussion above regarding what might count as a need and how needs might be prioritized is intentionally general. No specifics are offered. To do so here would be premature, given that it would presuppose a certain outcome from public deliberations. A public ethic of care could, however, offer a point of view about needs and their prioritization, how the meeting of needs should be met, and how best to deliver long-term care informed by an ethic of care.[35] The question of financing long-term care is one that is particularly well-suited to offering a point of view congruent with an ethic of care, and particularly fitting with our discussion of caring for frail elders. The chapter concludes with this discussion.

Financing Mechanisms for Long-Term Care Congruent with a Public Ethic of Care

Medicare and Medicaid, as noted earlier, are the two primary federal funders of long-term care even though neither of these programs were established to address long-term care. In addition to these federal programs, public financing for long-term care is available through various state programs, none of which are consistent from state to state, nor universal in their coverage within the state. Many are means-tested programs, and thus stigmatized, and targeted at the most poor and vulnerable.

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[35] Possible points of view espoused by an ethic of care to these questions is addressed in the next chapter.

Outside of public programs, other financing strategies for long-term care have been suggested, and some have been implemented. These include private long-term care insurance, tax credits, tax deductions, and medical savings accounts.[36] Although these differ in the details, they share common assumptions about who should be responsible for the provision of long-term care expenses, and all of these fall short in providing a mechanism for financing long-term care that is congruent with a public ethic of care.

Financing long-term care in a manner congruent with a public ethic of care begins with the assumption that interdependence between persons is a more accurate description of our common humanity than understanding persons as essentially self-sufficient and independent. As such, it is not enough to ask who deserves how much of what; instead we must consider whether particular funding mechanisms promote care for citizens as citizens, or whether they stigmatize and further divide people by their neediness. Is the need for long-term care recognized as a normal risk of living and can we provide funding such that when citizens need it, they can get it, without stigma of welfare, fear of impoverishment, or being alone? Furthermore, the provision of care is not something that rightfully falls to the private sphere or to the market; rather, it is recognized as a foundational social value alongside of liberty, justice, and equality which is owed to all citizens as citizens. Caring practices historically assigned to the private sphere are recognized as essential and valuable to keep society functioning well and thus belong to the entire society, not just to specific individuals. As such, a public ethic of care requires collective responsibility for

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[36] Further detail about the specifics of these options was provided in Chapter Four.

protecting the welfare of vulnerable groups, including those who do the work of care, and this should be apparent in our means of financing care.

Proposed financing mechanisms for long-term care that depend on the tax code, on the market, or on some marriage of the two are limited when assessed through the lens of a public ethic of care. First, not all citizens are workers; consequently they will not be able to benefit from tax incentives and likely will not be able to afford to purchase private long-term care policies or afford MSAs (Merlis, 1999).[37] Second, the division of citizens into workers and non-workers further marginalizes those unable to meet their needs for long-term care from their own resources. They become defined as needy and dependent, even though they may have spent their lives informally caring for others or performing care work for pay that barely reimbursed above minimum wage (Tronto, 1994, Sevenhuisjen, 1998). Third, apart from distinctions between workers and non-workers, other invidious inequalities are reproduced. Those who are healthy will be able to purchase more affordable long-term care insurance or find MSAs profitable; underwriting policies will preclude those with illness or disability from the same sorts of benefits. Thus, risk pools become more segregated, with higher premiums and/or less coverage for the more frail (Moon, Nichols, and Wall, 1996; Nichols, Moon, and Wall, 1996). Also, given the inequalities that already exist within the health care system, we know that poverty

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[37] Medical savings accounts are not yet proposed as funding mechanisms for long-term care. They are, however, available under Medicare. Given some attention to developing more integrated systems of acute and long-term care, MSAs are included here.

and disease are strongly correlated, and we know that poverty causes disease.[38] Link and Phelan (1995) assert that poverty is a "fundamental cause" of disease because lack of economic resources limits "access to resources that can be used to avoid risks or to minimize the consequences of disease once it occurs" (p. 93). Because such variables as race, ethnicity, and gender are so closely tied to economic resources or lack thereof, marginalized statuses "should be considered as potential fundamental causes of disease as well" (p. 93). These inequalities persist into older adulthood; if good care is dependent on being able to purchase affordable long-term care insurance, these populations continue to face barriers. Fourth, care remains invisible as a worthy public value. Care is defined as a commodity which one purchases on the market or to which one is entitled via participation in the labor force. It is something that one arranges for oneself or one's family members. The decisions one makes about securing long-term care often carry considerable individual risk. Purchasing private long-term care insurance for a future frail self is not an exact science. Deciding whether to join a MSA means assessing one's own risk for care and hoping that no serious illness occurs before the next open enrollment.[39] Finally, and implicit in earlier points, none of these options encourages a larger public discussion about our responsibilities to each other as we age. The purchase of long-term care insurance and weighing one's risks for a MSA are private, individual decisions. Such

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[38] The literature here is extensive. For starters, interested readers will want to consult Blendon, Aiken, Freeman, and Corey, 1989; Cooper, Simmons, and Castaner, 1986; Kahn, Pearson, Harrison et al., 1994; Padgett, Patrick, Burns, and Schlesinger, 1994; and Weissman, Stern, Fielding, and Epstein, 1991.

[39] See Nichols, Moon, and Wall (1996) for a quantitiave analysis of winners and losers under MSAs and catastrophic combinations of health insurance.

consequences as more deeply segregated risk pools and the perpetuation of two-tiered systems of care do not easily become matters for public concern.

Consequently, if we wish to bring a public ethic of care to bear on long-term care, we must identify responsibilities for funding such care in a way that understands the provision of care to be a societal responsibility. Typically, for costs that are potentially catastrophic and unpredictable, as is the case with our need for long-term care, we rely on insurance to spread risk.[40] Social, rather than private, long-term care insurance affirms our common need for care and our commitment to it.[41] Wiener and

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[40] As evidence of the unpredictability and catastrophic nature of long-term care, we know that there are a growing number of elders living longer but it is not at all clear whether they will be having more years of good health or more years of chronic disease accompanied by functional impairment. Even if morbidity rates stay the same, however, the sheer numbers of elders will likely translate into increased need for more long-term care. In terms of nursing homes as sites for long-term care, it is predicted that thirty-six percent of people age 45 living in the community in 1995 could expect to enter a nursing home at some point in their lives, on average, 38.6 years later. For those older than 45 in 1995, the likelihood of needing a nursing home placement rises steadily, and the years remaining before needing such care decreases. Most people who will need nursing home care will need it for less than one year; an average projected stay is 2.7 years. Seven or eight percent, however, of those age 45 in 1995 will need five to seven years of nursing home care. The costs for such care are devastating. Estimates for one year of nursing home care costs, on average, range from about $40,000 to $50,000. Lifetime costs projections for persons age 67 in 1995 were, on average for men, $56,895 and for women, $124,370. Other uncertainties in terms of long-term care more generally include the levels of need, new service modalities for delivering long-term care, availability of current resources such as nursing home beds and informal care-givers, inflation, fluctuations in payment sources, and so forth (Merlis, 1999).

[41] Beyond this important point that social, not private, long-term care insurance, makes public and visible our national commitment to frail elders, there are other constraints that limit the usefulness of private long-term care insurance (Merlis, 1999). Underwriting processes screen out high users. Studies estimate that between 12 and 23 percent of the population would be rejected under current underwriting practices if they applied for long-term care insurance at age 65; between 20 and 31 percent would be rejected if they applied at age 75. Furthermore, actuarial uncertainties make predicting costs and benefits difficult. Estimates regarding how many policy holders will live to claim benefits and for how long are imprecise.

Illston (1994) suggest that "coverage of long-term care on a nonmeans-tested basis will go a long way toward treating disability as normal risk of life rather than the failure of the individual deserving of public charity through welfare" (p. 407). Additionally, Merlis (1999) argues that a form of social insurance to which everyone contributed and to which everyone was guaranteed help when needed, ". . . depending on the financing structure . . . could effectively increase the national savings rate, promoting long-range economic growth. A social insurance program could also promote uniform quality standards and improved coordination between acute and long-term care services" (p. 2).

Critics of providing public long-term insurance make many good points.[42] A main concern is cost. The reluctance to create another open-ended entitlement program like Social Security and Medicare is understandably great. Furthermore, some fear the woodwork effect, that is people previously cared for by family members would come forth and require public resources for their care. Some are concerned that without means-testing, those who financially could pay for long-term care will not need to pay, while lower-earning workers will contribute to the long-term care needs of people who could well afford such care. Part of this worry

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While one might assume that insurance companies assume this risk, to get around this, companies can impose premium increases on all policy holders in a class (not individually). Insurees, then, pay the burden of poor actuarial estimations. Furthermore, although some policies are becoming more flexible, most are rigid in their design to cover certain benefits. Given that we do not know how services will be delivered in coming years, it is difficult to plan and purchase policies. Also, premiums do not vary by income; thus private long-term care insurance policies are a highly regressive way to finance long-term care. Finally, if fewer middle-class elders require Medicaid because of their own policy, the result will be a more entrenched dual system of care, with diminished care for the remaining Medicaid population.

includes the concern that those with high income and wealth we be able to leave larger bequests to their heirs. Finally, some critics argue that private long-term care insurance can more efficiently deliver needed services.

In response to concerns about costs, Merlis (1999) points to evidence that Americans are willing to bear some costs for expanded public long-term coverage. He also notes that such costs will be incurred whether or not we provide social long-term care insurance, and they will be paid for somehow. The primary effect here is redistributing the burden from individuals and from state Medicaid budgets to a national, universal pool. In response to the woodwork effect, or increased demand for services, Merlis argues that having private insurance will also increase such demand. Both public and private long-term care insurance options share the problem of "free riders." Hooyman and Gonyea (1995) remind that such care has never been free, but has fallen squarely on the backs of women. Public long-term care insurance, in addition to recognizing the invisible work of care, is a more just response to the provision of care. In any event , given the predicted shrinking pool of care-givers, this concern may be only academic; as the babyboomers age, there will be fewer adults to care for them (Estes, Swan, and Associates, 1993). In response to the concern of asset protection, Merlis wonders why this question arises with long-term care but not with Social Security or Medicare. Medicare in particular allows some very sick and wealthy people to avoid paying tens of thousands of dollars in hospital and physician bills, theoretically leaving more resources for heirs.

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[42] For useful summaries of criticisms of public long-term care insurance, see Merlis, 1999; Wiener, 1996, 2000; and Wiener and Illston, 1994.

In terms of means-testing, it could be asked whether it is not possible to do both, that is, those who can afford to purchase private long-term care insurance should do this, and those cannot afford it could receive public long-term care insurance. Likely this route is unworkable, suggests Merlis (1999). A two-tier system of care, such as we currently have with differential nursing home reimbursements for Medicare and Medicaid, will likely be perpetuated. If we were able to provide comparable care regardless of whether one had private or public insurance, middle-class people would not be likely to purchase private insurance. If we encourage greater reliance on private insurance, we risk reducing political will for those less off to have an adequate system of care. Merlis, in his response to the private sector efficiency argument, does not engage this question of efficiency; rather he allows that there may well be a role for private insurance plans with social insurance.[43]

Publicly funded long-term care insurance embodies, then, a public ethic of care for frail elders. Although it is beyond the intent of this project to map out the details of such a system, it is important to note, particularly in response to those skeptical about the costs of such care, that the United States has much to learn from other industrialized countries. Although U.S. citizens have never embraced a welfare state to the extent that some other industrialized countries have, and we have been far more ambivalent about the role of government in our lives than other countries, we have gone far in ensuring at least universal health care to those aged 65 or older. It is

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[43] Merlis has in mind here a process that would work similarly to Medicare. He also allows that long-term care could be consumed within a revised Medicare system, and this too would leave open the possibility of roles for private insurers.

not impossible for us to imagine this next step of universal long-term care insurance.[44] Germany, for instance, enacted a universal-coverage social insurance program for long-term care in 1994 (Cueller and Wiener, 2000). This replaced its means-tested program, which was criticized as degrading for requiring impoverishment before assistance.[45] The new program of social insurance was premised on a strong social belief that there must be collective arrangements that protect everyone from the unpredictablilities of life; thus far, it has enjoyed broad public support.

Germany's public long-term care insurance program was able to achieve many of its policy goals: it shifted the burden of care off the Lander (states) and municipalities; it increased support of informal care-givers; it lessened dependence on means-tested welfare; and it increased the supply of long-term care services. Universal coverage was financed by a 1.7 percent gross salary contribution shared equally by employer and employee (with one mandatory paid holiday eliminated to appease employers who objected about costs). To ensure that spending does not mushroom uncontrollably, revenues and benefits are capped. Revenues are limited by the fixed contribution rate while benefits are fixed by disability level and setting. If spending exceeds agreed upon levels, intentional political choices by government authorities are needed to balance funds. Eligibility is based solely on functional status as determined by medical offices; the minimal threshold for securing benefits is

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[44] While not impossible to imagine such a next step, not all are optimistic. Robin Stone soberly reminds that "we have neither the underlying philosophy of social solidarity nor the political will to create a social insurance program similar to the one Germany created. . . (2000, p. 62).

limitations in two ADLs and a need for help in some IADL. Three levels of disability are identified (substantial, severe, very severe), and at any level, one can choose institutional care, home care services (voucher for services), or cash (an income supplement to purchase services or care). The ability of the family to provide care is not a factor in determining disability. Three-fourths of beneficiaries receive care in the community, and 76% percent of this group choose benefits in the form of cash.[46] They do not have to account for how cash is used, and if given to a family member as payment, it is not counted as income. For further support, informal care-givers are given four weeks of respite care and also pension credit. Germany's policy goals were met without burgeoning caseloads or uncontrolled expenditures (Cuellar and Weiner, 2000).

Germany's system is not without concerns. Those noted include quality of care, particularly when care is purchased; a strong insistence on a uniform national program which translates into little variation in services across geographic areas or across individuals in same disability category; separate funding streams for acute and long-term care needs that create problems of cost shifting and coordination; lack of recognition for cognitive impairments, and concerns about efficiency (Cuellar and Wiener, 2000).[47] When viewed through the lens of a public ethic of care, its insistence on a uniform national program at the expense of being able to respond to variations in needed services across geographic areas or across individuals in the

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[45] The debate, in fact, was not about universal versus means-testing but rather how best to provide universal coverage (Cuellar and Wiener, 2000).

[46] The cash benefit is one-half the dollar amount of the service benefit (voucher).

same disability group is disappointing. On the other hand, maximum flexibility is provided to elders in terms of the site of care (home versus nursing care) and needed services; they and their families are able to implement a long-term care plan that more attentively responds to what elders' perceive they need. Germany's commitment to make care into a central and visible policy goal is commendable as well.

Japan, with 17 percent of its citizens already over the age of 65, provides another example of publicly funded long-term care (Campbell and Ikegami, 2000). On April 1, 2000, Japan moved toward "socialization of care" for the frail elderly by initiating public, mandatory long-term care insurance. This benefit covers institutional and community-based care, and represents a major shift from family care-giving to care-giving by the state. Medical and social services are integrated with unified financing. The program is financed through a combination of social insurance and general revenues; municipalities have the formal responsibility to determine how much it will spend for its eligible residents.[48] This expansion of the autonomy and management capacity of local government is seen as important innovation in Japan. Premiums are paid by everyone age 40 and older. Persons aged 65 and older, and persons older than age 40 with an age-related disability (i.e., stroke

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[47] The efficiency concern is that while cash payments further equity, "long-term care funds are spending a great deal of money to accomplish relatively little behavioral change" (Cuellar and Wiener, 2000, p. 23).

[48] The social insurance part (one-half of the revenues) of long-term care insurance is covered by two new premiums, one paid by workers over the age of 65 as a supplement to their health insurance, and the other a deduction from public pensions received by persons aged 65 or older. The remaining half of costs come out of general revenues: 50 percent national, 25 percent from prefunctures, and 25 percent from municipalities (Campbell and Ikegami, 2000).

or Alzheimer's disease) who meet eligibility requirement based on physical and mental disability in six categories of need can apply. Benefits consist of all services, no cash, and are generous, covering 90 percent of need. Consumers choose the services and providers they want, including the use of for-profit companies. Concerns expressed by policy analysts about Japan's program have mostly to do with cost, although interestingly, such concerns were rarely expressed during the decision-making process. From the perspective of a public ethic of care, Japan's commitment, like Germany's, to moving the care of frail elders into the public arena, thereby making care a central moral commitment, is commendable. And, even though it is too early to assess how well Japan has met its initial policy goals, its commitment to demedicalizing long-term care (as evidence by integrating social and medical services into one funding stream), giving consumers considerable latitude in choosing services and providers to meet needs, and moving management of the program as close to constituents as possible comports well with a public ethic of care.[49]

It is important to note that as Germany, Japan, and other industrialized countries sort out the issues of universal coverage for health and long-term care needs for elders, universal coverage in and of itself does not address the issue of defining needs. A decision must be made about what counts as a legitimate need that will be met under the blanket of universal coverage. Returning to points made earlier, a deliberative process similar to what Young (2000) puts forth - - a process congruent with a public ethic of care - - is needed to identify and delimit the range of needs that

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[49] Consumer choice and systems of care responsive to particular locales and individuals as practices congruent with an ethic of care are discussed later.

will be met by social insurance for long-term care. Unless a nation wants to allocate all of its resources to meeting the needs of frail elders, difficult rationing decisions will still need to be made. According to Shactman and Altman (2000), increased spending on the elderly has already crowded out or reduced spending in other important areas such as education, housing, and the environment. While the proportion of national income allocated to government spending is not fixed, it is limited, particularly given American's historic disdain for higher taxes. Thus we need to deliberate within the parameters of a fixed budget about what needs we will meet.

To sum thus far, in revisioning long-term care through the lens of a public ethic of care, a system grounded in meeting the needs of frail elders requires democratic deliberation to sort out questions of need and practices of responsibility. It requires that our defined needs for and responsibilities to provide care be undergirded by financing mechansisms that make visible a public ethic of care. Social insurance for long-term care is a most likely mechanism for doing this.

As noted earlier, deliberative discussions may not lead to consensus. It is likely, however, that the answers to these questions will be broader and more inclusive than the system of acute health care that Medicare brings to us, the model of institutional care premised on medical models that Medicaid delivers, or the commodification of care to which both systems default. Out of these diverse perspectives comes the opportunity to design and implement a system of care that is as responsive as possible to diverse perspectives and works towards meeting the needs of frail elders and their care-givers. Here a partnership with the state is particularly important.

Young (2000) notes that there are limits to what civil society can contribute in the public sphere. She writes: "I challenge this tendency to regard civil society as an alternative site for the performance of public-spirited, caring, and equalizing functions that have long been associated with governments" (p. 180). While democratic deliberations can offer significant opportunities for self-determination, such practices are limited in addressing justice as self-development.[50] The state is needed to correct for widespread consequences of market and profit-driven practices, practices that throw people out of work, divide the work process into cost-effective units divorced from any satisfaction inherent in doing one's work, and favor large-scale producers over local farmers and artisans - - in short, overcome practices that thwart "the organization of the necessary, useful, and creative work of the society so

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[50] Young defines oppression as institutional constraint on self-development, and domination as institutional constraint on self-determination. Deliberative discussions give opportunities for self-determination, that is, "being able to participate in determining one's action and the condition of one's action" (p. 32). Being able to participate in making the regulations of institutions can prevent domination. Self-development, however, means "being able to actively engage in the world and grow" (Young, 2000, p. 184). Self-development has to do with being able to develop and use satisfying skills in socially recognized settings - - being able to laugh, play, and express feelings. While it is more than meeting basic needs and distributing resources and material goods, market- and profit-oriented economic processes obstruct the ability of many to develop and use such abilities. Hence, self-development cannot rely alone on the communicative and organizational activities of civil society but requires positive state intervention to regulate and direct social life for the self-development of everyone.

that everyone able to make social contributions has the opportunity to do so" (p. 185). Young argues that:

> . . . left to themselves, both the organization and consequences of capitalist market activity impede the self-development of many people. Authoritative state regulation can limit the harmful effects of economic power. Economic and infrastructure planning, redistributive policies, and the direct provision of goods and services by the state can minimize material deprivation and foster the well-being of all members of society" (p. 189).[51]

To suggest that civil society with its opportunities for democratic deliberation in the public sphere must be linked with the state in formal processes of decision-making in our reform of long-term care creates significant tensions. In theory, says Young, they both perform complementary functions, "both limiting the potentially harmful effects of unfettered and merely self-regarding economic activity, and each correcting the potential excesses of the other" (p. 190). In practice, however, they can work against each other. The state's power can stifle civic activity and innovation, promote passivity among citizens, and ignore important differences between people and groups. Civic associations, by contrast, lack the coordinating function of the state, resulting in the possibility that they may work ignorantly of or at odds with other associations. Moreover, they are exclusionary, and increase fragmentation. When civic and political associations are strongly tied to the state, then it is more difficult to act independently of the state or hold it accountable to citizens. When

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[51] See pp. 180 – 184 in Young (2000) for her response to her libertarian, communitarian, and post-marxist critics regarding her argument for a strong state coupled with deliberative practices in the public sphere.

civic and political associations' authority is decentralized, it is easy to lose sight of the coordinating function of the state for society. There are no easy resolutions to these dilemmas; possibly the best we can do for the moment is to recognize "these ever present tensions and liabilities, be vigilant in monitoring the actions and effects of both state, economy, and civil society, and actively promote the limitation and balance of each by the others" (p. 195).[52]

The challenge of grounding long-term care in meeting the needs of frail elders, the starting point for a public ethic of care, requires the resources of deliberative democracy to identity and prioritize needs and determine responsibilities we have to each other. This process, usually connected to various conceptions of justice, is not at odds with what an ethic of care requires; in fact, it provides a framework in which the need for and practice of care can have a more central location in making political judgments. As well, it furthers the possibilities that the policies and judgments that arise in the public sphere are firmly grounded in a liberal, democratic, and pluralist society, and neither paternalistic nor parochial.

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[52] Young critiques the work of Hirst (1993) and Cohen and Rogers (1995), both of whom put forth arguments for associational democracy. Their arguments, however, serve to highlight the tension between state and civil society, rather than resolve it.

Chapter Seven
Care-giving and care-receiving: Re-visioning Long-Term Care Through a Public Ethic of Care

The final task in re-visioning long-term care in terms of a public ethic of care is to consider how policies that flow from a discussion of needs and responsibilities can establish and deliver opportunities in concrete situations of care-giving and care-receiving to affirm a social conception of the self, be contextual, and prioritize relationships.

We will have come far in establishing policies congruent with a public ethic of care if what has previously been suggested occurs. If the needs of frail elders are defined within a context of democratic deliberation - - where those who must live with the outcomes of the decisions are included as equal discussion partners, and where careful attention is given to understanding responsibilities to each other as they arise out of current practices - - we will have lessened the gap between those who care about/care for and those who give and receive care. In doing so, recalling Fisher and Tronto (1990), we lessen the chance for privileged irresponsibility. A successful deliberative discussion will have moved the concerns of care-givers and care-receivers to the public sphere, where those who make and enact policy are visible and accountable to the deliberators.

Moving more intentionally into the phases of care-giving and care-receiving, and working from concerns raised earlier about such care, what might be different for care-givers and care-receivers if public and organizational policy took seriously an ethic of care? What if care-giving were seen as a legitimate activity of the welfare state, codified in concrete policy, and recognized as valuable to the functioning of a healthy society (Weinberg, 1999)? What if care-receivers were perceived as deserving of public funds and benefits by virtue of rights that attach to citizenship, and the contributions of care-givers were recognized as valued social contributions and rewarded accordingly? And how might public and organizational policy regarding care-giving look if, rather than being developed in its historic piecemeal fashion, it was serious about affirming a social conception of the self, being contextual, and prioritizing relationships? The suggestions offered here are mid-range recommendations of what long-term care congruent with a public ethic of care will affirm in concrete situations of care-giving and care-receiving.

Integration of Acute and Long-Term Care

Policies that shape and direct care-giving and care-receiving will work toward integration of acute and long-term care. Some experts have noted that to speak of integration offers little about the structure or content of integration; in fact, such language is marked by a great deal of conceptual fuzziness (Callahan, 1999). In an effort to clarify what integration of acute and long-term care suggests, Leutz (1999) defines integration as "as the search to connect the health care system (e.g., acute, primary medical, and skilled) with other human service systems (e.g., long-term care, education, and vocational and housing services) in order to improve outcomes (e.g., clinical, satisfaction, and efficiency) (p. 77 – 78). As such, it encompasses integration of services and integration of funding mechanisms.

Leutz's five "laws" for integrating medical and social services offer a glimpse into the complexity of integration: (1) You can integrate all of the services for some of the people, some of the services for all of the people, but you can't integrate all of the services for all of the people; (2) Integration costs before it pays; (3) Your integration is my fragmentation; (4) You can't integrate a square peg and a round hole; (5) The one who integrates calls the tune (Leutz, 1999). In short, while integration of acute and long-term care services and funding streams makes sense conceptually, the knowledge and technical skills needed to do this effectively are only partial for the moment. Leutz recommends involving users, carers, and community service providers in planning and oversight as helpful steps toward integration. Furthermore, systems must be developed that have the capacity to work not only towards full integration but also coordinate and link services for frail elders. Finally, borders between medical and other systems must be clarified, and hopefully expanded. Expanding Medicare to cover more long-term care, and expanding Medicaid by requiring less stringent means-testing for long-term care services are a beginning, argues Leutz (1999)

Beyond this, of course, one can imagine that integration of funding sources would remove the distinctions between Medicaid and Medicare for elders. It might include, as well, other sources of revenue such as those that come through the Older Americans Act or a long-term care social insurance tax (similar to Germany, for instance). Additionally, some or all of the revenues of $111.2 billion dollars generated by the health tax expenditure would go far toward enhanced public long-term care or universal long-term care insurance. Minimally, a deliberation about how equitable the health tax expenditure is, given its skew toward benefiting high-income groups, can occur (Sheils and Hogan, 1999).[1]

Integration will not solve the problem of what needs will be met within an integrated system of acute and long-term care. For that, a deliberative process as discussed earlier is required. But surely a discussion occurring among those who will be affected by the policies established can be envisioned. What kind of care do we value when we are in need of long-term care? What kinds of benefits and trade-offs would we be willing to make? Do we value the extension of life at all costs, and thus, for example advocate for including LVADs as a benefit? Might we be willing to trade expensive treatment, such as organ transplants, for more extensive home, rehabilitative, or institutional care currently not covered in any substantive way? Might we opt for more extensive prescription or over-the-counter drug coverage, foot and dental care, or assistive devices for sensory impairments over high-tech interventions that may add only a short time to life? What, if anything, might we be willing to trade for social support, mental health services, or spiritual care? This is not to suggest that deliberations will result in a package to which all agree. If deliberation is done correctly, however, the voices of all those who are affected by the

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[1] The Health Tax Expenditure (HTA) is the amount of revenues the federal government forgoes by exempting employer health benefit contributions, health spending under flexible spending plans, and the tax deduction for health expenses from federal income and Social Security taxes. Those with incomes over $100,000 (10 percent of the population) account for 23.6 percent of all federal tax expenditures. Thirty-six percent of the U.S. population has incomes over $50,000; they receive 68.7 percent of the tax expenditure. In contrast, families with incomes under $50,000 comprise 64 percent of all U.S. families; they received only 31.3 percent of all tax expenditures (Sheils and Hogan, 1999). Not only would these resources go far in establishing universal coverage for long-term care, they would go far as well toward meeting the health care needs of the nearly 44 million uninsured Americans.

outcomes are respected, and the process by which decisions are made, including reasons given, are transparent and understandable to all.[2]

Regardless of how integration of services and funding occurs, integration maps onto an ethic of care in that selves are defined more broadly than being simply physical beings who can be restored to health and independent functioning. Integration of acute and long-term care recognizes the frailty and dependence many experience as they age. While such policies work toward restoration of health when possible or slowing decline in functional ability, they also recognize that social and supportive care produce other valued outcomes. Reducing loneliness and boredom, reminiscing with an eye toward achieving integrity, and assistance with basic tasks of living, for instance, communicate respect and worthwhileness to frail elders (Thomas, 1996). The enactment of collective rituals like mourning the dead, or participating in an outing that connects one back to earlier life experiences are reinserted into long-term care by an ethic of care against acute, often high-technology medical care (Diamond, 1992; Henderson, 1995). Activities and interactions directed toward a person's capacity for growth, or what Young would call "self-development," are given equal currency in allocation and prioritization decisions.[3] The practice of "social neighborhoods" within nursing homes, concrete affirmation that sharing food and drink are social practices carried out with friends and family, would be

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[2] Nor is the final package necessarily one package. It may be possible, for instance, to conceive of several options of integrated services from which elders choose. The MediCaring option, for instance, while of lesser appeal to elders aged 65 to 80, has potential appeal to those aged 80 and older (Lynn, O'Connor et al, 1999).

[3] Recall Young's definition of oppression as "institutional constraint on self-development" (2000, p. 31).

commonplace, low-tech "interventions" that mitigate against the serious problems of malnutrition and dehydration experienced by nursing home residents (Burger, Kayser-Jones, and Bell, 2000).[4] In all of this, attention to maintaining and preserving relationships with loved ones through restoration to health or continued decline is valued.

By integrating acute and long-term care, possibilities are opened up that the social care component of long-term care can begin to receive the same sort of systematic and careful attention to elders' needs and preferences that is currently given to medical care decisions (i.e., considerations about advance directives, for instance). This in particular furthers an ethic of care's commitment to providing care that is contextual. Carpenter et al. (2000) found that while the value of documenting preferences for medical care has received substantial attention, "relatively little theoretical or empirical work has been done regarding the assessment and implementation of preferences in the area of psychosocial care" (p. 335). Knowing psychosocial preferences is essential to providing respectful, individualized care, argue the authors, and without this, we rely on guesses, usually incorrectly, at what

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[4] "Social neighborhoods" within nursing homes center on a kitchen and dining area. Each neighborhood had about 20 residents. Describing the results of the change from traditional nursing home feeding procedures to social neighborhoods before the Senate Special Committee on Aging, Flagge reports the following:

> "Three important results of this change [to neighborhoods] are the increased socialization of residents, a decrease in unanticipated weight loss, and a decrease in wasted food. Residents sit around tables surrounded by their friends, eating a meal of their own choosing. Each meal is a social event, which family and friends are welcome to join. A minimum of two to three entrees is provided and anything that they don't find that they want, we can replace. . . We do not have a weight loss problem in our facility" (cited in Burger, Kayser-Jones, and Bell, 2000, p. 21).

people find important, or we rely on "cookie-cutter" templates to deliver psychosocial care. Damon-Rodriguez (1998) suggests that one of the most grievous ways we do this is through blanket use of U. S. traditions within nursing homes for all elders. Halloween, St. Patrick's Day, or Valentine's Day lacks meaning for some elders; by contrast, activities that support the cultural rituals and ceremonies of other traditions, such as making a 1000 cranes, Japanese kanrecki for 60th birthdays, or hwangap for Korean 70th birthdays, demonstrates respect for such traditions, connects elders to the larger culture that has provided meaning for them throughout their lives, and opens doors for careworkers to better understand their residents.

Taking Paid Care-givers Seriously

Policies congruent with a public ethic of care that shape and direct care-giving and care-receiving will take seriously the needs and contributions of paid care-givers. Economically, care-giving that impoverishes care-givers is unjust, and is at odds with a public commitment to value care alongside of equality and freedom. Low wages are particularly of concern in regard to nurse aides and home health care workers, whose per hour wage is barely among minimum wage, and often below the poverty level. These workers deliver 80 to 90 percent of hands-on care to frail elders. Among all formal helpers (physicians, nurses, social workers, and home health aides), these workers are rated by care-receivers as the most helpful person to them in their daily acitivities; informal care-givers also rate them as the most important person in terms of their stress-relieving ability (Bass, Noelker, and McCarthy, 1999). Yet home health and nurse aides must often work two such jobs to make ends meet (Diamond, 1992), leave their own children in less-than ideal care situations, and often go without basic benefits of health care (Bureau of Labor Statistics, 2000 – 2001; Crown, Ahlburg, and MacAdam, 1995; Weinberg, 1999). Low wages for service workers, argue some, is intricately linked to our disdain for dependency. Not only do we despise those who need help, we pay those who care for them a pittance of a wage because of our inability to notice normal and ordinary dependencies of everyday life (Sevenhuijsen, 1998; Stone, 2000c; Tronto, 1994). England and Folbre (1999) offer a more charitable read on low wages for service workers. They suggest that some believe that love and care are demeaned by commodification.[5] Caring is most effective when done for intrinsic reasons. The principle that money cannot buy love may "have the unintended and perverse consequence of perpetuating low pay for face-to-face service work" (p. 46).

Regardless of the thinking, or lack thereof, behind low wages for care-givers, an ethic of care moves this concern of low wages to the foreground. As a nation, the issue of how best to recognize caring labor as work and support the contributions of careworkers to the public good must be visible. England and Folbre (1999) suggest that the "public-good aspect of caring labor means that levels of service and pay for care-givers may depend upon collective action. It would be useful to study the roles that unions, worker initiatives, and state regulation play in defending standards of care and higher pay for those doing caring work" (p. 47). Similarly, Stone (2000c) calls for a care movement that joins together people who give care for a living,

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[5] Laws against prostitution, reflecting a belief that sexual intimacy should not be bought and sold, and laws that prohibit adoptive parents from buying babies (except to cover birthmother costs), fall into a similar category of logic that care and love cannot be bought and sold, according to England and Folbre (1999).

families who care for and about their members, and people who need care. Although these groups are split by their relationship to care, to the service sector they inhabit, and the sector of the economy that holds sway over needed resources, they must come together to effect change. Stone points to several "seedling movements" that are "inspiring models for a grand care movement," that "demonstrate the breadth of care as a political issue and the power of coalitions to put care on the public agenda," and which "prove the force of caring as a motive for political action" (p. 15). In Los Angeles in 1998, a group of home health workers for seniors and disabled persons unionized;[6] since unionizing, homecare workers have received a modest 50-cent pay raise (bringing them to $6.25 an hour). In San Francisco, where the union, the Public Authority, and consumer groups have been working together longer, the coalition has secured a $9 per hour rate, comprehensive health care, and dental insurance. The executive director of the San Francisco Public Authority asserts that better compensation is having a positive impact on the quality of care and attracting a more stable homehealth worker. Another organization, the Massachusetts Service Employees for Rights and Viable Employment (MASS SERVE), was founded by Rick Colbath-Hess, a social worker and father of two young children, who, in spite of his love for his work, had to quit in order to support his family. MASS SERVE unites workers, all of whom want to be in human service professions, who care for many different types of vulnerable people. Focusing on wage legislation, MASS SERVE led the way for a living-wage bill in the state legislature (in contrast to most

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[6] Seventy-four thousand homecare workers became union members, the largest influx of new union members since 1941.

living-wage laws that are local ordinances) that would insure that workers paid by state funds earn at least 135 percent of the federal poverty line for a family of four. The coalition is supported by the National Association of Social Workers, the Massachusetts Nurses Association, unions, Empower (an organization of mentally ill care recipients), Alliance for the Mentally Ill, and Mass ARC.

In addition to union efforts, local cooperatives also respond to the need for living wages for careworkers. Cooperative Home Care Associates began in the mid-1980s by Rick Surpin, an advocate for the poor, in the South Bronx. In its inception, Surpin noted two needs, better home health care and decent jobs for those on welfare. Today it is the largest inner city worker-owned home care agency in the country. The organization is a for-profit company owned by the more than 500 employees, each of whom has a vote about such things as pay increases, bonuses, and the board of directors. Employees earn about $8 an hour, work about 30 hours a week, and receive benefits such as paid sick leave, vacation, and additional pay for weekends or unusually difficult patient care. Overall, the agency has had huge success in helping people often deemed unemployable, primarily women of color on public assistance, to become reliable and competent home health care workers. The employment provided by the agency is more stable than most; the quality of care delivered is consistently rated at the top of New York service providers; and the program serves as a widely imitated example of a democratic, employee-owned company (Glasser and Brecher, 1997).

The success of the Cooperative Home Care Associates is attributed to more than just the wage it pays to employees because, all things considered, this still keeps employees near the poverty line if they have no other source of income. Its success speaks to other needs the cooperative meets, in large part, to the attitudes it holds toward workers. Both in recruitment and ongoing work, the cooperative values and respects the significant life experiences most workers come with - - often lifetimes of providing care - - and builds off these. Difficult patients are discussed collectively and seen as challenges for which to find solutions rather than simply complained about; the expertise of the workers is central to finding solutions. Ongoing education is provided for workers and home healthcare workers are used as instructors and leaders. Respect combined with opportunities for company ownership, leadership, and further education contribute to workers's satisfaction and competence. The director, Faith Wiggin, observes about her workers that "if you provide a quality job for the worker, the worker provides quality care for the patient" (Malveaux, 2000, p. 192) Such cooperatives have been reproduced in Philadelphia, Boston, Baltimore, and New Hampshire, and training centers have been established in Detroit and Pine Bluff, Arkansas.

Other organizations have found that some of the variables in the success of the Cooperative Home Care Associate are also key to their programs. Effective training with opportunities for continued professional development, advancement in one's position, a supportive and respectful work environment, and acknowledgement of workers' expertise in knowing what care-receivers need are also important for increasing satisfaction of workers and reducing turnover.[7] The Welcare program in

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[7] Worker turnover is a serious problem in both nursing and home settings. It averages 100 percent annually and can be as high as 400 percent (Cohen-Mansfield, 1997; Kettlitz, Zbib, and Motwani, 1998). The effects of this result in a reduction in the

Missouri, sponsored by the National Association of Geriatric Nursing Assistants, trains welfare recipients for the long-term care workplace and provides job placement assistance. Begun in March 1997, it provides 75 hours of instruction, 100 hours of clinical work, and 25 hours of professional/personal mentoring. In its one-year evaluation, 70 of its 84 graduates were still in their first job, and many had been recognized for their work (Porter, 1998). An unexpected outcome of an educational program designed to help nursing assistants communicate more effectively with persons with dementia was reduced turnover of nursing assistants (McCallion, Toseland, Lacey and Banks, 1999). The authors speculate that increased competence and less stress in working effectively with difficult patients contributes to workers' job satisfaction and a decreased desire to terminate employment.

Hyatt (2000) discusses several success experiences within nursing homes in term of recruiting and maintaining nurse aides. Mary Bartlett Paspalas, Vice President for Senior Services and Long Term Care for BJC Health System, affiliated with the Washington University School of Medicine, speaks to the intensive efforts of keeping good workers:

> "Once we hire an individual, no matter what the position, we need to focus on that employee with one thing in mind: How do we make this employee achieve success here and continue to want to work here? The issues go well beyond having an excellent orientation and impressing them in the early days of employment. We need to assign mentors, coaches, and buddies to help

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quality of health care for residents as well as additional administrative costs to recruit and train new workers. Cohen-Mansfield (1997) found that facilities can pay over $2,200 to replace one nurse aide.

> them in every aspect of the job, including technical training, coping skills, and even social issues on the job as well as off the job. We need to treat the employees with a 'care plan' as we do our residents. We must ask them what their goals are and what keeps them from achieving those goals, and intervene where feasible. Then we offer rewards to the employees as they achieve their goals" (Hyatt, 2000, p. 17).

Because the work of home health or nursing aide is perceived as a "dead end" job in spite of it being key to overall patient and family satisfaction, some organizations focus on developing a career ladder (Ebenstein, 1998, R. Stone, 2000). Pine Valley Care Center of Richfield, Ohio created a system of upward mobility in terms of status and salary for nurse aides directed by increased knowledge and advanced skill levels acquired through a core curriculum and a specialty area of competence. As workers passed the curriculum, their efforts were noted with salary increases, graduation and promotion, and increased responsibility. In terms of outcomes, the care center was noted as the top nursing home for nurse assistant satisfaction, and the turnover in nurse aides decreased from 82 percent in 1996 to 16 percent in 1999 (Moffatee, Stefanini, Hardke-Peck, 2000).

In addition to a career ladder, some programs have found that self-managed work teams (SMWTs) increase nurse aide satisfaction with their work (Yeatts and Seward, 2000). These teams are responsible for both technical and management aspects of their job. The teams work together daily on tasks related to care-giving and management concerns such as schedules, sharing information with next shift, and so forth. The findings indicate that workers complete more work than in hierarchical settings, that their decisions are effective because they are made by workers closest to residents, job satisfaction increases due to greater involvement in decision-making and higher levels of team cooperation and cohesion, and there is less turnover (Thomas, 1996; Yeatts and Seward, 2000). Thomas (1996) notes that the management style of most nursing homes differs little from that of an army regiment with its clear hierarchy of authority and tightly managed daily routines with rules and regulations that spill over into the care of residents. Arguing that "nursing home residents and community-dwelling care recipients can never be more empowered than the staff who care for them," Thomas is also a strong advocate for SMWTs where nursing assistants schedule their own hours, and work out their responsibilities among themselves once they arrive (p. 46). From an ethic of care, those closest to the care-giving encounter have valuable knowledge and expertise to contribute on what is best for their patients and themselves.

Nursing assistants also speak to the need for adequate staffing levels. In the few studies that have addressed the perceptions of nurse and home health aides about what is important to do their work effectively, patience, compassion, empathy, and respect for care-receivers, are cited as important qualities. Having time to develop a relationship with care-receivers is noted as an important structural variable (Ebenstein, 1998; Schwartz, 2000). When nursing homes or home health care agencies are understaffed, however, workers must rush through their work at great cost to what they find valuable in their work as well as potential harm to care-receivers.[8] Schirm, Lehman, and Barton (1996) found that when short-staffed, workers still do the necessary work but do it more quickly; "when these behaviors are engaged in, quality care that includes fostering social interaction, maintaining adult status, providing choice, and allowing residents to consult in the care they receive is neglected" (p. 102). Harrington, Zimmerman et al. (2000) found that although shortages of nursing staff, social workers, and administrative staff led to particular deficiencies in care within nursing homes, shortages of nurse aides led to deficiencies in total care, quality of care, and quality of life.[9]

Development of an adequate workforce to do the hands-on carework is one of the most pressing concerns facing long-term care in the future (R. Stone, 2000). A public ethic of care requires that these workers be able to earn a living wage. If the needs of others for care are met by exploiting a sub-population of people - - likely women, particularly women of color - - historical exploitation of women as care-givers within families is reproduced in the public sphere. The labor divisions and

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[8] Burger, Kayser-Jones, and Bell's study (2000) speaks powerfully to the need for sufficient numbers of workers for feeding times at meal times. With current practices of one worker being responsible for feeding 7 to 9 residents at noon and 12 to 15 residents in the evening, it is not surprising that malnutrition and dehydration are serious problems in nursing homes.

[9] Lower levels of RN staff are significantly associated with total care deficiencies and quality of care deficiencies but not quality of life deficiencies. Lower levels of other care staff, including social workers, are associated with increased quality of life deficiencies. Lower levels of administrative staff are associated with increased deficiencies in the administrative category of total care. In terms of the categories, quality of care includes 72 specific items from the federal survey category such as resident assessment, nursing services, dietary services, and so forth, as well as specific outcomes such as prevention of pressure sores, falls, and physical decline. The quality of life category includes 77 specific items from resident's rights such as admission, transfer, and discharge rights. The total care category includes items drawn mostly from administrative and medical records (Harrington, Zimmerman, et al. 2000).

material conditions of care-giving that shape our lives and our experiences as care-givers and care receivers cannot be ignored. The need for careworkers to do their work with adequate compensation is a matter of justice; likely this can only occur when the need for care is recognized publicly alongside other treasured national values. Within organizations that deliver care, the policies and procedures that shape the culture of the carework environment - - staffing ratios, career ladders, self-managed work teams, and respect for the knowledge of care-giving that comes from concrete carework encounters - - must be recognized as integral to providing attentive and responsive care.

Taking Unpaid Care-givers Seriously

Policies congruent with a public ethic of care that shape and direct care-giving and care-receiving will take seriously the economic needs and contributions of unpaid or informal care-givers as well. Just as with paid care-givers, economic impoverishment as a care-giver is unacceptable from a perspective of justice and a perspective of care. Furthermore, given the gendered nature of informal care-giving, women's long-term economic security is threatened, even if impoverishment does not occur, as informal care-giving carries with it no contributions to Social Security or pension plans. From a public ethic of care, the value and work of care-giving remains private and invisible, something individuals attend to if and when they can no longer care for themselves. In part, because care-giving is non-monetized, bewildering scenarios emerge, as discussed earlier. Many families want desperately to care for their loved ones, but in the absence of financial assistance, they cannot afford to terminate or reduce employment. Even if a family is able to provide informal care, out-of-pocket costs related to health care are burdensome to many. Other families may not be able to provide the needed hands-on care for a loved ones, given their own failing health, geographical distance, or some other factors. In the absence of affordable options for care of a loved one, they must arrange piece-meal care-giving plans, hire low-wage workers through informal networks, and/or leave care-receivers without needed care. Some families may not wish to provide hands-on care and some care-receivers would prefer not to receive such care from loved ones. Unless these families have significant financial resources to hire help, they are forced to assume such responsibilities themselves. Scenarios such as these generally do not contribute to sustaining loving relationships most families value, nor do they promote care that respects the needs and preferences of all involved - - benchmarks of an ethic of care. Economic pressures, to say nothing of emotional pressures, weigh heavily on care-givers and care-receivers.

To take seriously the economic needs of care-givers so that both an ethic of care and an ethic of justice is realized, however, raises complex questions about how this should occur. One of the most challenging questions is whether or not family care-givers should be paid or, similarly, whether care-receivers should receive a stipend to contract independently with a potential care-giver.[10] Those against direct cash payments to family care-givers argue that such practices exploit family care-

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[10] Although paying spouses or family members is not permitted under HCFA Medicaid regulations for personal care, as a matter of practice it does occur in 35 states through waivers or Social Security Block Grants. However, there is no grand plan here; direction is lacking on the federal level, and great variation exists among the 50 states in whether and how they might reimburse family care-givers. Even in states where this practice is allowed, caps often limit available dollars (Hooyman and Gonyea, 1995).

givers in that it pays them less than the market rate under the banner of "consumer-directed services." The payment system is designed, critics argue, to ensure that families and friends provide as much care as possible, with as little assistance (including no benefits) as possible. Some care-givers report feeling "trapped by a system that did not value care-giving and did not provide sufficient reimbursement to attract a qualified and quality workforce" (Blaser, 1998, p. 66). Interestingly, in revising Japan's long-term care system, Japanese feminists were very vocal about not offering care-givers payment for this very reason, fearing that low payments would further oppress women to remain in low-paying care-giving jobs given social, economic, and political pressures to keep women in these roles (Campbell and Ikegami, 2000). Not only gender but class bias would be reinforced as well because the incentive payments, in order to be as cost-effective as possible, would so low as to be an inducement to quit work only to the poorest paid workers (Abel, 1991).

Other concerns about direct payment for family care-givers include the potential for fraud and abuse. No oversight of care generally occurs. When the care-giving stipend is valued by the care-giver, care-receivers may be threatened to cooperate through intimidation or out of fear that a nursing home placement will be next, or simply not be willing to report inadequate care because he/she knows that the income is needed. With such incentives, care can become distorted as emotionally ill-equipped care-givers continue to care for economic incentives alone (Kane, 1986). And while systems that might be put in place to offer training and monitor quality are possible, these will increase the costs significantly; this combined with payment stipends will increase program costs by five times the current amount, assuming present need stays constant (which it will not, given changing demographics and woodwork effects) (Blaser, 1998). As well, care that family members "owe" each other becomes commodified when reimbursed. Rather than payments to care-givers, critics recommend increases in services.

Others suggest that payments to families who provide care should be available.[11] Such practices would, rather than reproduce inequalities in carework for women, "improve gender and class justice by placing a monetary value on the labor of a primarily female, low-income workforce" (Simon-Rusinowitz, Mahoney, and Benjamin, 1998, p.70). Particularly for low-wage minority women most vulnerable to impoverishment in later years and who have limited opportunities in the paid labor force, such an arrangement makes it easier for them to "make a commitment to that work, decrease the financial penalty associated with it, and legitimize their work at a modest public cost" (p. 70). While wages might be low, whatever level of financial assistance is available is desperately needed; "by demanding that caretaking be divorced from the cash nexus, we sentimentalize women's unpaid labor on behalf of their families. Women provide care not only out of love and concern but also out of a sense of obligation" (Abel, 1991, p. 169). Furthermore payments to families to provide care or secure care recognizes consumer choice, which correlates strongly with service satisfaction (Simon-Rusinowitz, Mahoney, and Benjamin, 1998). In response to those who argue that cash payments commodify care, remuneration in

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[11] Ironically, Medicaid bars relatives from reimbursement who are legally liable for a family member from receiving payment for personal assistance, but permits all others relatives do so and pays them a contractual rate for care based on a needs-assessment and subsequent authorization for a given number of hours of care.

and of itself does not prevent high quality, individualized, particular care from being offered as evidenced by best practices in traditional 'caring' professions of social work and nursing; as well, nonpayment for care does not guarantee that good care is delivered (Abel, 1991; Himmelweit, 1999; Hooyman and Gonyea, 1995). Finally, offering payments expands the force of available workers. In one California study, about one-fifth of family members paid to assist had not done so before entering the program. Given the predicted severe shortage of workers, Simon-Rusinowitz et al. (1998) argue that this option pragmatically cannot be overlooked.

For those who argue that families should receive payment for care-giving services delivered by themselves or to hire assistants, there is no settled consensus on what kind of model program of reimbursement would be best. Should the purpose of payment be to offset the expenses of care-giving or to compensate care-givers for services provided? How should a wage be set? A shadow wage that parallels what one might earn in the paid labor force would be appealing to those with high education, experience, and well-paying jobs, but for others, such a wage would reinforce class and economic differences. A universal wage based on what nurse or home health aides usually earn would be more equitable but also very low. Furthermore, should payments be made directly through cash subsidies or through tax incentives, be means-tested or universal in coverage? And who serves as gatekeeper in terms of defining functional needs assessments? These are difficult and complex decisions (Abel, 1991; Himmelweit, 1999; Hooyman and Gonyea, 1995).

From the perspective of a public ethic of care, paying families for care-giving responsibilities is appealing in many ways. Care-receivers and families are in control of securing help that is a good match between care-giver and care-receiver. If hired care-givers turn out to be inattentive, incompetent, and not invested in the care relationship, their employment can be terminated. If family members want to provide care, and care-receivers want to receive care from them, then theoretically those bonds of love and intimacy in all of their particularity, so integral to family relationships, are strengthened, while financial pressures are reduced. Furthermore, a visible statement is made about our public valuing of care.

But serious concerns exist as well about this option's congruence with an ethic of care. Japan's feminists were exactly on target with their concern about continued gender and class inequities being perpetuated under this system, particularly if wages remain as low as they are currently for nurse and home health aides. While a full-blown revolution of informal careworkers perhaps will be warded off, little will have been done to change the current inequities that persist for unpaid care-givers, and in fact, may have made it more difficult for deeper social change to occur. Furthermore, token payments for care-giving are more a matter of cost-containment - - a mechanism by which to entice families into care-giving as an alternative to more costly institutional care - - than a social good which attaches to citizenship. As Abel (1991) reminds, however, to delineate the difficulties is not to argue that the question of payment be abandoned nor the mechanisms by which it should occur.[12] Asking

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[12] See Ungerson (2000) for an interesting examination of various kinds of payments for care that exist cross-nationally. She cautions that injecting cash into the fragile care-giving relationship must be carefully considered. In her qualitative study of people with disabilities, she found that care-givers did not feel exploited and felt free to leave if they wanted. On the other hand, "there are delicate negotiations happening here, pitfalls encountered, bricks dropped, and traps entered into" (p. 88).

questions consistent with Walker's (1998) understanding of ethical responsibility being embedded in interpersonal relationships, we could consider our common understanding about responsibilities we owe to one another and ask whether there is anything morally troubling about paying family members to do what some think they should do anyway. We would want to consider whether eldercare differs in morally important ways from caring for our children, whose moral evaluation of the situation counts, and ask whether there are other options as yet unconsidered that perhaps fit better with our understandings of caring for elders.

Apart from the contentious issue of payment to families for care-giving responsibilities, other mechanisms have been proposed as partial solutions to making it possible for those who wish to care for family members to have that choice (Arno, Levine, and Memmott, 1999). Tax credits and amendments to the Family and Medical Leave Act to be more accessible to employees in small firms, while limited in terms of material assistance, are symbolic gestures in recognizing the need for care as a public responsibility. Both are limited, however, in their dependence upon employment and connecting care to the notion of citizen as worker. Some have proposed awarding Social Security credits to care-givers during the care-giving years or allowing more drop-out years (i.e., ten rather than five) to be excluded in the computation of benefits (Beedon, 1992; Kingson and O'Grady-LeShane, 1993). Changes such as these would begin to recognize that unpaid carework delivered in the home is of value to the marketplace and to society as a whole. Cornman and Kingson (1996) warn, appropriately, that whatever we do, our broad discussions about how to respond to the needs of an aging society should not begin with a conversation about what entitlements the country can afford over the next 50 to 75 years. To ask this question casts "too narrow a net and to frame the questions associated with population aging in a manner which, if accepted, focuses attention primarily on questions of how best to shrink federal commitments" (p. 24). Rather the conversation needs to begin with an understanding of the broad trends and issues facing an aging society and the public values that should drive public policies in the future. Casting care-giving issues as transfers "may serve to elevate the visibility of much informal care-giving, increasing the likelihood that these issues will emerge as explicit public policy concerns" (p. 23).

Responsive, Individualized Care

Policies congruent with a public ethic of care that shape and direct care-giving and care-receiving will allow nursing and home health agencies to provide individualized care that is responsive to unique care-giving situations. The tensions here are several. Public policies in and of themselves cannot deliver care. They are intended to ensure that those in need of long-term care receive it through some form of distributive justice. This is what is expected of public policies. Similarly, organizations cannot deliver care in and of themselves. They too have an obligation to distribute their goods and services in a way that is fair and equitable to its constituents. Most of us would be justly angered by an organization that delivered a higher level of services or goods to one person, while seeming to ignore or treat differently someone else similarly situated. Only people can deliver individualized, respectful, attentive, and responsive care. The question, then, becomes one of determining how agencies and organizations can set policy that allows care-givers to deliver good care, without violating principles of fair and equal treatment, and provide care-givers with "opportunities, skills, and contexts that allow them to deal with their patients in caring and compassionate ways (Scott, Aiken, Mechanic, and Moravcsik, 1995, p. 81).

Movement toward creating policies that allow care-givers to deliver attentive and individualized care can occur by beginning to value and use the knowledge and expertise of those closest to the care-giving situation - - paid and unpaid care-givers, family members, and care-receivers. Those who make and implement policy must move in close to these players, and work collaboratively with them. Groups of politically astute resident councils, patient coalition groups, care-giver groups, and frontline careworker unions - - all of whom have very little authority over day-to-day operations of delivering long-term care - - must be mobilized to act for change based on what they experience and perceive to be good care delivered and received.[13] Consider how life in nursing homes might be different, for instance, if the experiences of Mr. Nelson Mead, a 91-year old nursing home resident, were given serious press. He writes:

> If we recognize that the primal nature of human beings is to seek fellowship, human understanding and inward comprehension, fostered by mutual inspiration and concern, then the nursing home becomes a very pernicious and inappropriate form of confinement . . . while concentrating on the medical and

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[13] Diamond notes that care-receivers, family members, and paid and unpaid care-givers "are up against a medical model of a hospital, with professionalized job descriptions and state regulations, a business with prices and profits, a model of rationality and cost-effectiveness, and a discourse ideologically loaded with words like *care*" (1992, p. 233).

> habitational aspects of such facilities, the *in corpore* [physical] items mentioned earlier, we often overlook the *mens sana* [mental health] portion of the equation. . . . Maintenance of normal physical functioning can well be considered as primary, but without the assurance of being happy, competent and fully alive, to what degree can we appreciate good health (1991, pp. 12 – 15).

Diamond (1992) argues that those at the interstices of care, caught between administrative rules and regulations and the practices of care to frail elders, have enormous knowledge and potential for power. They have knowledge of internal needs and external controls, knowledge of how to stretch scarce resources, and knowledge of how to calm and comfort a demented person. "Mother's wit" includes attitudes, skills, and practices, often made invisible by medical discourse, related to "feeding, cleaning, teaching, laughing, comforting, holding, scolding," . . . skills and practices that work toward "making into a home that which has been made into a hospital" (p. 243). Taking this knowledge seriously, and using it as a basis for making organizational and administrative policy suggests that many of the insights noted earlier by nurse and home health aides are integral to delivering attentive and responsive care. To do their work well, nurse and home health aides need a supportive environment in which to discuss problems in care-giving that arise with particular patients, and ongoing education based on what they experience as gaps in learning. They need adequate overall staffing and reasonable time frames in which to work so that they are not rushed and forced to minimize basic skills of conversation - - Young's skill of greeting (2000) - - in exchange for meeting deadlines. Workers who have experienced success in the use of self-managed work teams have found ways to insert more control into their work, and also found more time for doing their work in a way that has integrity in terms of maintaining good care (Scott, Aiken, Mechanic, and Moravcsik, 1995). These experiences that are grounded in concrete care-giving should be foundational to organizational and administrative policies.

Public policy also needs to be informed by care-receivers, care-givers, and family members. The way in which Medicare and Medicaid affect the concrete care-giving situation was discussed earlier. Certainly those policies need rules and regulations to guide implementation. The rules and regulations, however, need to be informed by those closest to care-giving. Rules and regulations regarding what counts as necessary medical care, for instance, need to be informed by physicians and other health care providers in particular, as well as by larger deliberations among those who stand to benefit from Medicare policies. They should not be set by administrators of reimbursements systems, as is the case now. Similarly, clinical standards that are flexible, that can respond to unique and individual situations, that have room for the experiential and intuitive knowledge of direct care staff, and that recognize the social component of care, are important for public policy, even though this stands in tension with objective rules necessary to meet the demands of procedural justice. Current clinical standards for home care, for instance, come from large, aggregate, statistical data sets based on historical patterns of expenditures for different kinds of patients (D. Stone, 2000b). These are inadequate; instead, such standards need to be developed by people close to the care situation, including professionals, laypersons, and paraprofessionals. The latter for instance, know how much time is needed to bathe and clothe a person, and how such tasks vary from person to person. Using this knowledge, policy can be built using consensus committees rather than large aggregate statistical analyses. Finally, in terms of medical care, physicians, nurses, social workers, therapists, and aides should be able to classify patients into treatment groups based on careful assessment. Classification should not be done by intermediary agencies, as is the case with the newly emerging Medicare system where OASIS data is used to classify patients and determine reimbursement.

Additionally with Medicare, rules and regulations that spell out what constitutes fraudulent practice are likely needed. Again, those closest to the care situation should be intimately involved in developing standards and rules that make sense (in contrast to the vague and arguable rules that currently cause such great grief). Furthermore, those closest to the care-giving situation should be given more authority in considering what counts as fraudulent. Scrutinizing the medical and documentation standards of care should be done by committees or agencies consisting of various professionals, insurers, and consumers, not government agencies or insurance companies that represent only payers. The process should be one of mutual informing; "[Payers'] judgments need to be tempered by the judgments of people who understand the concrete situations of care recipients, just as care-givers' loyalties and sympathies need to be tempered by fiscal realities" (Stone, 2000b, p. 27).

Finally, in terms of Medicare, Medicare policy must be developed and implemented intentionally to complement and support informal care systems (Stone, 2000b). When considering the impact of Medicare on frail elders, the unit of analysis needs to be expanded from the care-receiver alone to the social support network. Mechanisms must be in place such that care-givers and care-receivers can respond to proposed Medicare changes in terms of how they affect their lives. Seemingly positive changes in Medicare can adversely affect some groups of beneficiaries. For instance, adding Hospice as a Medicare benefit legitimized and institutionalized better care practices for dying persons; the full-time care-giver rule, however, disenfranchises those without such a person in their lives and potentially places burdens on care-givers that are too great (Nelson, 2000). Any new regulations or rules to Medicare should include an explicit analysis of how the proposed changes will affect informal care-giving (Levine, 1999).

Medicaid policy also needs to be informed by care-givers (paid and unpaid) and care-receivers in terms of the dimensions just described. The medicalization of nursing homes in tandem with their development as an industry in which payments pass directly from the federal/state government to providers creates the politics of long-term care (Hawes, 1997 – 1998). This arrangement gave birth to attending economic interests that need protecting, and has created tremendous pressure for deregulation in the nursing home industry. The political power of nursing home owners is significant. In 1996, nursing home operators contributed more that $1.1 million to the Clinton campaign; many attended the infamous White House "coffees" for major donors (Weisskopf, 1997). Similar events happened at the state level, with the bottom-line effect of leaving care-givers and care-receivers out of negotiations as far as quality and costs of care. It also leaves them out of the negotiations as far as what kind of care they value most in terms of quality of life. Such factors as social support (Stevens, 1992), family support (Farber et al., 1991), and realizing expectations for one's life (Ghusn et al., 1996) are correlated to quality of life for frail elders, and these are goods furthered by sound psychosocial interventions.

Even though the 1987 OBRA nursing home reforms led to the most far reaching revisions to nursing home standards, inspection processes, and enforcement since the inception of Medicaid, and indeed resulted in needed improvements, nursing home residents today experience malnutrition and dehydration at rates of third world developing countries (Burger, Kayser-Jones, 2000; Harrington, Zimmerman et. al., 2000; Kayser- Jones, Schell et. al., 1999). These basic deficits in care are not captured, generally, by elaborate charting protocols.[14] Nurses aides are assigned too many patients to feed, much less chart accurately their consumption. Quarterly MDS reports do not ask for data that accurately report malnutrition and dehydration, and thus do not trigger further assessment with RAPs. The accuracy of the MDS itself, both at intake and quarterly, is compromised by inadequate staffing (Burger, Kayser-Jones, and Bell, 2000). Burger et al., in contrast to these methods of documenting care, uncovered malnutrition and dehydration through a longitudinal, qualitative study in nursing homes. Being present on nursing home floors and observing feeding

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[14] Diamond in particular takes issue with how medical discourse and medical charts become the concrete repository of documentary reality. In this type of discourse, the submerged narrative of workers and residents as they interact is silenced. Diamond suggests that residents and staff redefine and expand medical charts or develop another set of records that records everyday life. While medical expertise might not be challenged, the overarching dominance of this model in everyday life might be deconstructed. What would then be challenged is the external control residents experience; also the basis for the exchange of care commodities would be supplanted with narrative of actual practice of meeting the needs and desires of residents.

regiments and charting protocols led them to their findings, findings which likely were not a surprise to residents, their families, or nursing assistants given their proximity to the care relationship.

Consider the recommendations of Burger, Kayser-Jones, and Bell (2000) to the problems of malnutrition and dehydration. They recommend instituting a minimum direct care staff ratio at meal times of one nurse aide to every two to three residents with adequate management and supervision of staff by nurses. They recommend that all nursing home personnel be trained to assist in meal time feeding alongside of training volunteers and family members to assist. Regular inservices should be offered on how to feed and hydrate frail residents. A homelike environment - - a social neighborhood - - should occur at mealtime; foods should be properly prepared, attractive, and reflective of ethnic preferences. Furthermore, nutritious snacks and drinks should be available to residents at all times. The Body Mass Index screen should be added to the MDS as a trigger for evaluating nutritional status. The system of tracing nutrition/hydration needs to be streamlined and sufficient time must be given for accurate charting. These researchers and others also recommend increasing RN, LPN, and nurse aides such that residents receive more that 3.5 hours of direct and indirect care in a 24-hour cycle (Harrington, Kovner, Mezey, et al , 2000). These recommendations are not high-technology interventions, nor are they high cost medical procedures. They do require additional human resources and commensurate pay. More difficult, they require that the social and physical needs of frail elders are not traded for profit by nursing home owners, or ignored because of expense by those responsible for Medicaid budgets.

Encourage and Preserve Relationships

Policies congruent with a public ethic of care that shape and direct care-giving and care-receiving will allow for relationships between care-givers and care-receivers to be preserved and encouraged. In both home and nursing home care, care-giving dilemmas emerge that threaten to destroy or weaken care-giver/care-receiver relationships. Kane and Levin (1998) suggest that the "most exquisitely difficult ethical dilemmas that arise in home- and community-based services concern the proper boundaries between promoting freedom for older people and avoiding interference with their life goals, on the one hand, and acting responsibly to promote their health and safety on the other" (p. 76). In working with dementia patients, benign manipulations of patient behavior (i.e., bribes of cookies or candy), telling "white lies," or using chemical or physical restraints to ward off more severe or potentially dangerous behavior come at the expense of possibly eroding patient dignity (Hasselkus, 1997). Differences of opinion between family members about how best to care for aging parents, or differences between generations in how they prioritize such things as love and connection versus making one's own decisions, are potential threats to networks of family relations (Nelson and Nelson, 1998).

Additional moral binds that care-givers face in their work to preserve relationships and provide good care were described earlier; these kinds of moral burdens entail being caught in the middle between agency auspice and client and client's family, between the intimacy and closeness of care-giving and the formal rules of performance. Homecare workers sometimes manipulate categories of patient need, even though they put their job on the line or their agency at risk of audit, to be certain that a confused Alzheimer's patient is reminded to eat. On their own time, they run errands for care-receivers. Occasionally they enfold lonely and isolated care-receivers into their larger extended families, even though agency rules prohibit this. Nurse aides are no less immune from such moral burdens. Working against schedules that preclude a quiet ten-minute conversation with a resident, they push on, against the dictates of what their professional and experienced intuitions tell them constitutes good care, to complete and document their required tasks. If they stop to care, ironically, they risk reprimand or termination. Both groups of workers must struggle with tensions when care-receivers wish to reciprocate their thanks in ways that fall outside traditional professional guidelines. Accepting gifts or tips or being invited to a care-receiver's family event, for instance, practices that characterize relationships between good friends and allow care-receivers to express appreciation, are often forbidden by employing long-term care organizations. If workers choose to honor these tokens of appreciation from care-receivers, guilt and fear accompany their actions. In short, dealing daily with conflicts between public norms about caring and private practices over what constitutes good care is hard moral work. Stone (2000a) puts it this way:

> "People who must constantly violate rules, standards, and norms in order to do what they think is right must also work to fend off feelings of guilt and fears of getting caught, of losing their jobs, and of hurting their clients. In studies of burnout and high turnover among care-givers, fear and guilt management do not get much attention. The usual policy responses to burnout and turnover are to give more training to care-givers and to offer

> support groups. These responses miss the mark, for they do not address, or even acknowledge, the underlying moral conflicts of caring work. The policy problem for the future is how the ideals and practices of good care can be preserved in the face of pressures from professional, civic, workplace, organizational, and business cultures. To make caring better, we need to learn from the ideals of care-givers and from their underground behavior - - the ways they follow the spirit rather than the letter of their job descriptions. We need to learn from good care-givers how to price good care and how organized, public caring work undermines good care. If we want people to enter and stay in caring jobs, we need to face up to the moral conflicts of caring work and not wish them away with training and support groups" (p. 111).

Stone's assertion that we must learn from care-givers about how to do good work is addressed earlier in the context of using such expertise to inform and shape the implementation and delivery of public and organizational policy. But implicit in Stone's comment is another suggestion, and that is we must find a way to face up to and work through the moral conflicts to which care-giving relationships give rise. If we are serious about an ethic of care informing care-giving and care-receiving, ethical frameworks that pay attention to individualized, contextual, and relationship-affirming practices of care must be used.

In home and nursing home care, ethical ideals of autonomy, beneficence, and justice are too unidimensional according to Moody (1983); "[w]hen real conflicts arise, codes of ethics generally give no clue as to how to reconcile competing principles" (p. 103). Several researchers have pointed to the need for "everyday ethics" in long-term care settings, an ethic that can be used in close and intimate situations (Hasselkus, 1997; Stone and Yamada, 1998). Stone and Yamada (1998) argue that such an ethic "recognizes human need for affiliation and responds to the myriad of issues that arise from day to day, not a set of ethics procedures that are trotted out for large life decisions" (p. 46). Skills of attentiveness and responsiveness - - being able to recognize how social position shapes and affects one's ability or constraints to be autonomous, or being able to bring to the foreground the perceptions and experiences of all those involved in the care relationship - - are integral to everyday ethics. Holstein and Mitzen (1998), in a line of thinking very similar to Walker's ethic of responsibility, remind us that:

> [m]orality is embedded in the day-to-day practices of life, manifested through actions that reveal our fundamental values, commitments, and beliefs; it is an expression of our identity. As practitioners, we live our morality every time we enter a client's home by the greetings we offer, by the quality of our touching, and by our attentiveness as much as by giving the client choice (p. 10).

Ethical frameworks congruent with an ethic of care draw from many conceptual resources. Feminist ethics, wary of atomistic constructions of individuals as self-contained and autonomous, and resistant to a one-principle system of ethics, include attention to relationships between family members and care-givers. Waymack (1998) suggests that communicative ethics, with its emphasis upon ethical decisions as the outcome of a discussion in which the voices of all involved parties are heard, is essential "as each and everyone of these individuals is in some sense a participant in the delivery of care" (p. 14). Narrative ethics helps us determine responsibilities in the concrete by understanding previous histories of trust and expectation, and earlier applications of norms and values (Walker, 1998). Holstein and Mitzen (1998) summarize the kind of outcomes consistent with ethical frameworks that take seriously preserving and sustaining relationships:

> . . . we can ask ourselves what good we wish to achieve in our practices, what our aims are, and how we can assess our movement toward them. Achieving those aims might mean not guaranteeing a specific form of autonomy specific to our elder clients but rather having a conversation in which care-givers and care recipients each talk about what they hope this practice of care-giving will express in terms of, for example, responsibilities, or consideration, or compassion, or trust. At the end of the day, we can ask, Did our resolution of the moral problem sustain the integrity of each person and the relationships among all parties? Did we protect or enhance some valued good? Can we account for our actions in publicly transparent ways?" (p. 10).

While ethical frameworks congruent with an ethic of care are needed to inform concrete care practices, organizations must have structures in place where employees can discuss difficult moral burdens they bear. Stone's home care workers (2000a, 2000b) expressed that they had nowhere to go with tensions they experienced in trying to deliver good care and the imperatives of the organization for what constitutes professional behavior. Consequently, workers went "underground" in doing for their clients what they felt good care entailed, but such practices brought guilt and fear. McCurdy (1998) argues that while individuals have a responsibility to create and maintain ethical organizations, workers also need their organization's moral support and encouragement to do good and right things. Organizations need to develop mechanisms to address ethical issues that go beyond monitoring compliance to a code of conduct. Rather, they must develop mechanisms that will help it be continually and consistently reflective about its moral responsibilities; thus, above all, "the ethical organization is one that is continually alert to and reflective about ethical questions, with an eye to establishing – where possible – standards or accepted ways of approaching issues, while also recognizing the provisional, reviewable nature of the standards and practices that it develops" (p. 27). In particular, McCurdy recommends the use of ethics committees or ethics-centered groups that are accessible to all workers. If the climate of such groups is one in which workers can be open about their covert behavior, and free to discuss the tensions they experience in trying to deliver good care that does not always comport with agency standards of professional behavior, the goal of supporting relationships between care-givers and care-receivers stands to be furthered. Furthermore, given that "burnout" of workers is highly correlated to organizational and administrative variables, including lack of recognition to the demands of the job, the possibility of reducing worker turnover exists (Scott, Aiken, Mechanic, and Moravcsik, 1995).

To revision long-term care through a public ethic of care at the concrete level of care-giving and care-receiving, then, suggests that we consider policies that will integrate acute and long-term care systems, that are attentive to the needs of paid and unpaid care-givers, that allow for responsive care to unique and individualized care-giving situations, and that allow for relationships between care-givers and care-receivers to be preserved and encouraged. Although no long-term care system has been envisioned intentionally to map on to the requirements for a public ethic of care, there are existing models which, while not a perfect fit, do begin to approximate this. In particular, Programs of All-Inclusive Care for the Elderly and the Eden Alternative are useful to briefly consider as exemplars.

Programs of All-Inclusive Care for the Elderly

Prior to the 1997 BBA, Programs of All-Inclusive Care for the Elderly (PACE) were HCFA-waiver demonstration projects, extensions of the On Lok program developed in San Francisco's Chinatown – North Beach in 1971. Community leaders believed that a combination of health and social services would help neighborhood elders remain in their own homes and delay or prevent nursing home placements Grant funding from the Administration on Aging and Dept of Health Services of California started On Lok's community adult day health center in 1973. From this, the PACE model developed (Eng, Pedulla, et al (1997). Under the 1997 BBA, PACE became a permanent provider under Medicare and a state option under Medicaid. The PACE model is also recommended by the Michigan Long-Term Care Work Group (June 2000) as a component of each of its four different approaches to financing and delivering long-term care in the state of Michigan. As of July 1999, 18 developmental and 25 capitated PACE sites in 18 states served more that 6,000 participants (Wieland, Lamb et al, 2000).

As a program, PACE goals include maximizing the autonomy of it participants, continuing community residence, and providing acute and long-term quality care at lower costs (Kane, Illston, and Miller, 1992). HCFA goals for PACE include reducing fragmentation and integrating acute and long-term care into a single, seamless system (Vladeck, 1996). PACE's target population is frail elders at least 55 years of age and certified by the state as nursing home eligible. It is the only program to date to target frail and impaired elders where the providers assume full financial risk (White, 1998). On average, PACE enrollees are 80 years old (30 percent are 85 or older), dependent in 3 ADLs and 4 IADLs, and have an average of 7.8 medical conditions. Fifty-five percent of participants have bladder incontinence, and more than two-thirds suffer from mental disorders including depression and dementia. PACE participants are an ethnically diverse group: 45 percent are Caucasian, 26 percent are African American, 15 percent are Hispanic, 12 percent are Asian/Pacific Islander, and 2 percent are "other" (Clark, 1998). Thirty-nine percent of PACE participants live alone in the community, and 14 percent have no means of informal support.

PACE programs emphasize preventive and rehabilitative services to stabilize chronic conditions, and avoid or decrease disease complications. Its services are delivered in the PACE center, the home, or inpatient facilities. Each center has a day health center, a full service medical clinic, social and rehabilitation services, and recreation and personal care services. On Lok also offers supportive housing, an option other sites are considering as well, for those with no family care-givers. Each site is open 5 to 7 days a week, and each PACE site has at least one center open on weekends. Each site also has homecare. Specialty and ancillary medical services as well as community-based long-term care services (i.e., transportation, meals and personal care services when not at the center) are coordinated through the site. Most centers serve 100 to 120 enrollees; average daily attendance is 50 to 70 participants who come to the center several times each week, if not daily (Kane, Illston, and Miller, 1992).[15] Participants' medical conditions are briefly assessed and follow-up, when needed, is provided. They receive assistance with bathing and grooming. Recreation programs or a quiet place to rest are available. Lunch is served. In the afternoon, participants are returned home. A home health aide helps with meal preparation, chores, personal care, and bedtime preparations if no other informal care provider is available. Because all services are coordinated through the site, coordination is efficient and timely. PACE staff include physicians, nurses, social workers, occupational and physical therapists, dieticians, recreation therapists, transportation workers, and personal aides (Eng, Pedulla et al, 1997; Hansen, 1999).[16] This interdisciplinary team, which is the core of the PACE model, assesses each participant upon enrollment, makes decisions about service allocation, and continues to assess, treat, and monitor participants.

Both services and financing mechanisms for acute and long-term care are integrated in PACE. PACE sites receive monthly capitation fees from Medicare and

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[15] Sites operating four or more years have 375 enrollees on average. On Lok had 793 participants at the end of 1998 (Chatterji, 1998).

[16] See Eng, Pedulla et al (1997) for examples of typical schedules of selected team members. PACE social workers are involved daily in interdisciplinary team meetings, charting and record-keeping, assessments and monitoring of participants, new intake and quarterly assessments, home or hospital visits, collateral contacts with family members and other community providers, and, along with other staff, assists with serving lunch.

Medicaid[17] Medicare payments are based on the adjusted average per capita cost methodology used to reimburse Medicare HMOs, and are set to provide at least five percent savings to Medicare. The monthly Medicare capitation payment in 1998 ranged from $877 to $1,775. Medicaid capitation rates are based on state-specific estimates of the fee-for-service costs for comparable long-term care populations (either home and community based or nursing home care). Monthly rates ranged from $1,750 to $4,301 (White, 1998). Overall, average monthly capitation from all income sources is $3,388 per participant (Eng, Pedulla et al, 1997). All payments are pooled by the PACE site; the site is financially at risk for services provided, without limits on dollars or duration. Once enrolled, participants pay no deductibles or co-payment fees for health services. With "no out" and no place to shift costs, PACE manages its financial risk by keeping participants as healthy as possible with preventative health services, frequent monitoring of enrollees status, and wise use of team resources. If participants need hospitalization or nursing home placement, these costs come of the PACE budget.

PACE outcomes have been assessed in several ways. In contrast to 43 percent of U. S. health expenditures, On Lok spends only 17 percent of its capitation dollars on acute or nursing home care, leaving 83 percent of capitation dollars for home- and community based care (Bodenheimer, 1999). Other PACE sites report similar percentages. Savings to Medicare in the first six months of operation average 38

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[17] Sites might also receive payments from individuals; those ineligible for Medicaid may pay that portion of the monthly fee themselves. On Lok, for instance, has worked to create a package program for frail elders covered only by Medicare; these participants pay $2,009 per month to the program. Although lower than the $4,000-

percent and 16 percent in subsequent months; Medicaid savings range from 5 to 15 percent (White, 1998).[18] Disenrollment rates of 0.9 persons per month are considered low (Eng, Pedulla et al, 1997).[19] PACE has also reduced the use of hospital and nursing home care. In 1998, 2,224 inpatient days per thousand annually were used by PACE enrollees as compared to 2,014 for *all* Medicare beneficiaries age 65 or older (Chatterji, Burstein et al.1998). Only about 7 percent of PACE participants are in nursing homes (Gong and McCarthy, 2000). There is no increased mortality among PACE sites; in 1993, 138 deaths/1000 in PACE sites were reported versus 186 deaths/1000 among nursing home residents (Eng, Pedulla et al, 1997). Finally, there is a higher rate of job satisfaction among health aides in PACE settings than in traditional nursing home settings. Higher rates of satisfaction are correlated to the work environment of PACE settings rather than characteristics of employees. "Respect for my suggestions by people who make decisions about patient care" was the most highly ranked item by all health aides in terms of importance, and operationalization of this was found most frequently in PACE settings, where working as a team is integral to practice. Other important elements in job satisfaction

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plus cost of nursing care in San Francisco, it is still to high for most (Bodenheimer, 1999). Generally, participants "spend down" until they are Medicaid eligible.

[18] Critics have suggested that PACE is able to save money because it enrolls people who are less disabled than the average frail nursing home resident. Abt Associates, the research firm studying PACE under contract with HCFA, did not find selection bias, though its research method was not adequate to provide a definitive answer (Irvin, Masset, and Dorsey, 1998). Furthermore, because PACE is underenrolled (caring for about 7000 participants out of a potential 3 million frail and disabled adults), it does not have the "luxury" of cream-skimming. Abt Associates suggests that reduced costs occur because the PACE model is an effective approach for providing care to the elderly (White, 1998).

[19] The usual reason given for disenrollment is that participants wish to return to the care of their private physician (Eng, Pedulla et al. 1997).

include the opportunity to organize daily workload, respect for choices in the types of assignments, and the chance to use personal judgment; the latter two elements were found more frequently in PACE models (Friedman, Daub, Cresci, and Keyser, 1999).

Several limitations to PACE programs exist. First, PACE sites take time and money to develop. On average, three to five years is needed to develop a new PACE site and about $1.5 million is needed before the site is eligible for waivers (Bodenheimer, 1999). Also, PACE programs are considered "boutique programs," having appeal to a limited population (Leutz, 1999). Currently, PACE has limited attraction for middle-income frail older adults because they are not Medicaid-eligible. Third, recruiting primary care physicians and other health care salaried staff is difficult in many parts of the country. Few have special training in geriatrics. Eng, Pedulla et al. (1997) are hopeful that as geriatrics training receives more curricular currency in graduate education, employment in PACE sites will become more attractive. Fourth, the staff-model structure of PACE sites is outmoded, and likely a deterrent to enrollment. Some PACE sites are currently exploring the possibility of making arrangements with private physicians in the community, in tandem with close participation of nurse practitioners at PACE sites, such that this can occur (Bodenheimer, 1999). Fifth, among PACE sites, there are widely varying incomes from capitation rates. Under the 1997 BBA, reductions in capitation rates are predicted. Even though some studies indicate that Medicare is already underfunding PACE, HCFA, under the 1997 BBA, is requiring PACE programs to adjust Medicare capitation payments for participants using the HMO-capitation procedures of risk formulation. It is yet unclear how this will affect PACE programs (Bodenheimer, 1999). Finally, although positive about the PACE program, Leutz (1999) argues that evaluating PACE programs (as well as other waiver programs such as Social HMOs) in terms of saving money is very difficult to do because so many are in place. After a few years, it is difficult to identify the underlying state plan to which the waiver is being compared; "in short, the waiver process has become a de facto vehicle for policy change rather than a process for deliberate policy testing" (p. 92). In a similar vein, Branch (1999) reminds us that nursing home owners have higher costs of room and board and providing three meals a day. PACE administrators do not pay room and board costs and pay for only one meal. PACE participants can continue to receive SSI checks while nursing home residents forgo these. Subsequently, teasing out cost-effectiveness is difficult to do.

In spite of these limitations, there is much to recommend in PACE from the perspective of an ethic of care. PACE has done a commendable job of integrating acute and long-term care. In fact, these services are "intermingled to the point where they are difficult, if not impossible, to separate" (Kane, Illston, and Miller, 1992, p. 771). The meeting of acute medical needs is not prioritized over rehabilitative or preventative care; health care in general is placed alongside of meeting social, recreational, and personal service needs. Furthermore, because discussions with participants about end-of-life care are built into the initial assessment and ongoing review of participants, palliative care can be seamlessly integrated into the participant's care plan (Eng, Pedulla et al. 1997). The integrated pool of funds, in tandem with an interdisciplinary team who knows the participants, allows for individualized, responsive care that can be quickly modified as changes in well-being occur. The interdisciplinary team in conjunction with the participant and the family can determine jointly what kind of care is best suited for the elder; they are not bound by rules and regulations that arbitrarily count some services as legitimate and others as fraudulent.

In terms of formal and informal careproviders, PACE programs maintain high expectations for family members to be involved in care planning and actual care of PACE participants. If it is assumed that many family members want this kind of involvement, an assumption that the empirical literature supports, PACE enables family members to assume these responsibilities with significant support. The day health center model, for instance, offers day-time respite care for family members, and home care workers assist with personal care if no family member is able to assist. In theory, at least, the significant support offered by PACE in care-giving works toward preserving relationships among family members, neither overwhelming them with carework nor excluding their significant expertise and will to care. In terms of formal care-givers, the interdisciplinary team model reduces care-giver isolation and brings together the expertise of many fields in assessment and intervention planning. It creates a context in which the knowledge and experience of multiple disciplines, para-professionals, family members, and care-receivers can converge to make respectful and appropriate decisions about care planning (Eng, Pedulla et al, 1997).

The PACE structure also allows for each PACE site to collectively sort through its own ethical dilemmas. Bodenheimer (1999) points to some of these: Should cognitively impaired and nonambulatory persons receive a motorized wheelchair? Which participants with dementia should receive donepezil, a medication that costs more than $100/month? How many hours of help per week from a home health aide should someone at risk of falling receive? Difficult decisions about limiting care and making tradeoffs exist in spite of integrated services and integrated funding mechanisms. These decisions involve rationing the resources of PACE programs because economic resources are not limitless. When limits must be set, however, they are agreed upon by the interdisciplinary clinical teams that discuss among themselves, with participants, and with families, the particulars of each participant's situation. One can imagine that such discussions involve attention to the details of care-receiver's health and psychosocial needs, their housing situation, and need for personal care. As well, the resources, limitations, and motivations of family care-givers can be part of such discussions in setting limits, and preserving important connections between loved ones. What is clear is that limits are not set by PACE executives or administrators, or by Medicare or Medicaid regulations, people and policies presumably at some distance from the care-giving situation. Clinical autonomy and responsive attention to individual participants is a cornerstone of PACE (Bodenheimer, 1999).

Finally, it is important to note that while Medicare and Medicaid are the primary funders of PACE sites, PACE sites develop out of local community initiatives and partnerships. The On Lok program began in 1971as a system of loose coalitions to change long-term care. Program providers, private foundations, and state and federal governments were involved in launching On Lok as a demonstration project. As subsequent demonstrations were launched, an "each one teach one" method was used to replicate successful programs. In each state, regulatory environments and market conditions needed to be addressed collaboratively. It was recognized early on that no one person, group, or vision for long-term care would be the perfect answer. Particularly in terms of rate-setting, rates needed to be negotiated state-by-state, mindful of existing programs, policies, and political climates (Hansen, 1999). The process was time-consuming and frustrating in many states, but for those who endured, the end result has been a PACE site that is responsive to community and elder needs for long-term care, not a "one-size fits all" model, while using the resources of state and federal government. Although not perfect, PACE is a promising example of how federal and state entitlement to long-term care can result in systems of care that are responsive to political, geographical, social, and human diversity.[20]

Although PACE is a promising application of a public ethic of care, its fit with an ethic of care could be even stronger by considering the following. First, as noted earlier, PACE is a boutique program that responds to frail elders who are both Medicaid and Medicare eligible. If the PACE model is to become more widespread, a public program of financing long-term care is needed; as discussed earlier, public and universal funding (in contrast to such mechanisms as private long-term care insurance and tax incentives) for long-term care visibly demonstrate our collective responsibility to care and our commitment to care as a national value. Second, none of the literature reviewed addresses the wage structure of nursing and home health aides. This suggests that the wage structure for these workers parallels others in

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[20] Hansen (1999) reminds that one of the lessons to be learned from PACE initiatives is that the perfect should not be the enemy of the good.

similar jobs.[21] As discussed earlier, this wage keeps aides at or near the poverty level, and potentially interferes with their ability to care for themselves or other dependents. To care for frail elders while further marginalizing careworkers is both unjust and uncaring. To remedy this, a public and sustained conversation is needed about how best to pay living wages to these workers. Unions and organized labor are needed to push the discussion along and professions committed to further justice, such as social work, must lend their energy and expertise to such efforts. Third, in theory PACE models seem promising in working out a system of care that supports, rather than further burdens, informal care-givers. Whether this is the case is an empirical question, one which seems not to have been addressed yet given the absence of this discussion in the empirical literature.

The Eden Alternative

PACE programs are a promising example of home- and community-based long-term care that accord with an ethic of care. Although they work toward preventing nursing home placements, likely there will always be some need for the latter. Consequently, it is helpful to consider the Eden Alternative in light of nursing home placement.[22] The Eden Alternative is described as a philosophy, not a system, of long-term care.[23] It aims to reduce what founder William Thomas identifies as

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[21] Presumably, a higher than average rate for aides would be cited in the literature as one of the variables for success.

[22] The Eden Alternative philosophy is currently being extended to non-institutional settings, although this project is in its infancy. Called "The Green House Project," this initiative hopes to provide community-based homes to care for small groups of frail residents (ideally 6 to 8 persons per home). Information about the project can be accessed online at www.thegreenhouseproject.org.

[23] The Eden Alternative philosophy has also caught the attention of the Michigan Long-Term Care Workgroup (2000) as one strategy for developing "creative living

three plagues of nursing homes: loneliness, boredom, and helplessness (Thomas, 1996). These arise because nursing homes have a flawed definition of caring that is conflated with a medical model of diagnosis and treatment. The alternative, argues Thomas, is to conceptualize nursing homes not as high-tech treatment centers but as habitats fit for humans where they can flourish. To fulfill this goal, an institutional model of care must be retired, and a home-like environment that includes children, pets, and plants must be implemented (Couzens, 1999; Thomas, 1996). It is, however, much more than transforming nursing homes into "animal kingdoms," argues Thomas Zwicker, administrator and owner of Lakewood Care Center in Milwaukee; essentially it is about changing the strategy and structure of the long-term care industry that has been run more like a business than a care facility, and which models medical systems of hierarchy and power (A Long-term Care Paradise, 1999, p.13). One of Thomas' founding principles, that top-down authority be replaced with maximizing the decision-making authority of both residents and those closest to residents as care-givers, undergirds Zwicker's observation. Team management that encompasses all employees is integral to this process. Tavormina (1999) notes that the emphasis upon decision-making and self-management "filters down to empowering residents to make choices to provide diversity in their own lives and not just exist from day to day" (p. 160). Residents are included in day-to-day decisions such as menu-planning and outings.

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environments;" it is not given a great deal of attention, however, in the report. The Eden Alternative has also been recognized by the Joint Commission for its innovation.

Residents not only receive care but are encouraged to give care as well to children, to plants, and to animals. Programmed activities are de-emphasized, and resources saved are used to support the maintenance and growth of the habitat. After-school programs, on-site day care centers, school volunteer programs, and summer camps integrate children into the daily life of the home. Companion animals (usually dogs, cats, and birds) live in the home; they are not merely brought in for an afternoon of "pet therapy." They are included in the life of the home because interaction with pets is meaningful to many people. Beyond this, however, the burgeoning literature on the relationships between animals and humans, and animals' positive effects on elder functioning in terms of improving cardiovascular functioning, stimulating a greater sense of responsibility, and promoting increased interpersonal interactions, is well-documented (Haggar, 1992; Jorgenson, 1997; Kongable, Buckwater, and Stolley, 1989; Rosenkoetter and Bowes, 1991). Tending plants within the nursing home or tending vegetable and flower gardens outside offer additional opportunities for residents to do what many of them have found meaningful earlier in their lives.[24] Spontaneity and a variety of "natural" experiences, in contrast to scheduled activities, are emphasized with the integration of children, plants, and animals (Kane, Kane, and Ladd, 1998; Stermer, 1998). Judy Thomas, an Eden Alternative partner and advocate, summarizes the philosophy of care this way: "End the rigid hours residents must keep for meals, baths, and bedtime; let them sleep in the mornings if they choose. Throw out the time clock and let workers schedule themselves" (Levine, 1997, A36).

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[24] See Thomas (1996) for practical tips on integrating children, animals, and plants

In spite of the intuitive appeal that Thomas' vision has, only about 150 nursing homes nationwide have implemented the Eden Alternative. The commitment to more egalitarian staff relationships is one barrier. Even if the commitment exists, reshaping the rules-driven culture found in many nursing homes takes many hours of staff training. Cost is a further barrier. Staff training and continuing inservice is expensive, estimated by some to be at about $100,000 annually; care and upkeep of plants and animals accrues an additional $10,000 to $15,000 each year (A Long-Term Care Paradise, 1999). Some see the addition of plants and animals as gimmicks, and miss the underlying restructuring that must occur (Weinstein, 1998).

In spite of these costs, however, other cost-savings have occurred. Faxton St. Luke's, located in Utica, New York, and the Lakewood Care Center in Milwaukee, have saved between $2 and $2.50 per resident per day in pharmacy expenses (A Long-Term Care Paradise, 1999). Most of the decline has come from needing fewer anti-depressant medications and sedatives. Employee turnover rates have decreased; in Zwicker's organization turnover rates were as high 125 percent in 1993, before "edenizing." Today, turnover rates are at about 48 percent. Stermer (1998) reports similar experiences with lower staff turnover. In the original Eden Alternative project, set up as a research study in 1991 at two comparable nursing homes with one serving as a control, decreases in urinary track infections, upper respiratory track infections, and mortality rates (15 percent fewer at 18 months; 25 percent fewer at two years) were found. Additionally, there was a 26 percent lower turnover rate of nurse assistants, resulting in increased savings from recruitment and training costs.

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into nursing home environments.

Medication use was 38 percent lower in the Eden site, netting a per day, per resident saving of 88 cents. These findings have been replicated since the original study (Thomas, 1996).

Like PACE, several aspects of the Eden Alternative hold promise for its congruence with a public ethic of care. Institutional environments are modified in terms of structure where traditional hierarchies of staff are replaced by a more egalitarian system of self-managed work teams. As well, the infusion of children, plants, and animals respond to the social and emotional needs of residents, recognizing that more than just physical/medical needs must be addressed. The rigidity in schedules characteristic of many institutional settings are relaxed by de-programming of artificial activities, and the integration of more natural and spontaneous interactions with other residents, children, and animals. Even though care is provided consistent with (and within the constraints of) nursing home rules and regulations, this care is not routinized; individual wants and needs of residents are carefully assessed and responded to. Just as significantly, it is assumed that residents not only need care but can give care. Tending to children and gardens at a level commensurate with interest and ability, for instance, responds to residents' needs to engage in meaningful tasks and contribute to the life of the community. Intergenerational relationships are nurtured and sustained within the context of everyday experiences and interactions individualized to respond to what each resident values for him/herself.

There are unknowns as well about the Eden Alternative philosophy that preclude evaluation of its congruence with an ethic of care. One of the major criticisms of Eden Alternative sites is the lack of outcome evaluation. Individual sites have begun to do a more careful job of outcome evaluation in terms of variables such as medication use, reductions in chronic problems (i.e., bedsores, incontinence, irritability, and depression, for instance), mortality, and staff turnover. These studies are just emerging in the empirical literature to support the positive anecdotal reports from staff, residents, and residents' families. These studies tend, however, to be site-specific, and do not include control groups. Furthermore, no meta-analysis of Eden Alternative programs has been conducted to date. Consequently, several dimensions of Eden Alternative programs' congruence with an ethic of care are unknown. Although anecdotal evidence points to higher worker satisfaction concerning their role in patient care, and higher satisfaction of residents and families concerning the care received, exactly how this satisfaction correlates with Eden Alternative initiatives is unknown. Furthermore, there is no reason to believe that direct-line care-givers in Eden Alternative nursing homes are earning wages higher than those in other settings. Finally, it is unclear how Medicaid patients fare in terms of access to Eden Alternative nursing homes. Thomas Zwicker reports that a positive outcome of "edenizing" the Lakewood Care Center has been an increase in private pay residents, an increase in beds, and a decrease in Medicaid revenues from 90 percent to 85 percent of total revenues. Similarly, Faxton St. Luke's two facilities' percentage of private pay residents stands at 12 to 13 percent, up from 4 to 5 percent in 1996 (A long-term care paradise, 1999). This does not automatically suggest that Medicaid patients are being denied access to such facilities; more information is needed to make such a claim. It does, however, raise the question of who benefits from such care. If private pay residents stand to benefit most from Eden Alternative strategies, and the very poor are left behind in traditional institutional nursing homes, the requirements of a public ethic of care are not met.

In summary, revisioning long-term care at the concrete level of care-giving and care-receiving points to developing policies that integrate acute and long-term care systems, that are attentive to the needs of paid and unpaid care-givers, that allow for responsive care to unique and individualized care-giving situations, and that allow for relationships between care-givers and care-receivers to flourish. Models of long-term care such as PACE and the Eden Alternative, although not developed intentionally to reflect a public ethic of care, do indeed help identify ideal practices and relations of a public ethic of care for long-term care, even if present only partially, and provide a useful framework from which to work.

CONCLUSION

Chapter Eight
A Public Ethic of Care and Social Work

Before beginning the work of this final chapter, it is useful to summarize the arguments furthered and contributions made thus far. The multiple problems that attach to long-term care in the United States, evaluated through the lens of an ethic of care, are a result, in part, of various failures to intentionally care about and care for the needs of a frail elderly population. At the concrete levels of care-giving and care-receiving, competent and responsive care is difficult to deliver given an assortment of public and organizational policies that define and shape care work, and which do not necessarily value a social conception of self, contexualized knowledge of care needs, and preserving relationships. Instead, medical models undergirded by assumptions of restoring one to full productivity, cost-saving economic strategies undergirded by individualistic assumptions of providing for oneself, and conservative ideologies of families *qua* women as care-givers dominate the landscape of long-term care.

A public ethic of care is proposed as a response to the problems in long-term care. The argument furthered is that when used as a framework through which to revision long-term care, a public ethic of care holds promise for responsive public and organizational policies and programs that will respond accurately and responsibly to the needs of frail elders. These responses are built upon certain assumptions of human relationships and human nature- -that we are interdependent rather than autonomous and self-sufficient, and that our need for care is typical of human experience, not reflective of personal or moral shortcomings. Consequently, rather than assigning care responsibilities to the private sphere of the family where care-givers are often treated in unjust and uncaring ways, or to the market where care is commodified, the right to give and receive care is a central and public moral value alongside of equality and liberty. A public ethic of care does need, however, the resources of democratic deliberation, to do its work well. A public ethic of care at the concrete level of care-giving and care-receiving holds promise for developing practices that reflect concern for both formal and informal care-givers, that deliver individualized and responsive care across a continuum of acute to chronic need, and that work at preserving relationships between older persons and loved ones. Included here is care that attends not only to heath care needs but also emotional, social, spiritual, and psychological concerns. This stands in sharp contrast to current predominant medicalized models of long-term care framed in economic discourse.

The contributions that this dissertation attempts to make were noted in Chapter One and most have been developed. In terms of the larger disciplinary and professional conversation about an ethic of care, the usefulness of a public ethic of care in a specific context of long-term care, the constitutive elements of an ethic of care, and attaching need identification and prioritization to democratic deliberation have been argued. Long-term care has also been re-visioned through the lens of a public ethic of care. In doing so, current institutional and public long-term care policies and policy proposals that support long-term care have been examined. Issues of financing long-term care, assuming responsibility for long-term care, and needed supports for those who do the work of care in a manner commensurate with a public ethic of care have been addressed.

The final contribution this dissertation makes, the focus of this concluding chapter, is appropriating a public ethic of care for the social work profession from current larger and lively discussions in philosophy, sociology, and political science, in particular, and bringing this perspective into a field of practice significant to social workers. The question this chapter addresses is one of the relationship between a public ethic of care, gerontological social work practice, and more broadly, the social work profession. This chapter argues that a public ethic of care is not only congruent with the values and commitments of the social work profession but that it is a perspective which, if taken seriously by the profession, will lend further legitimacy to the aims of the profession and serve as an empowering organizational concept in direct practice, policy, and research. Free from essentialist feminine trappings that confine care to women's work in the private sphere, an ethic of care requires that at the level of direct practice, services be delivered competently and responsively to individuals. A public ethic of care also entails responsibilities to care about and for institutions and social structures that support and sustain caring. As Manning (1992) states, "if we understand our obligation to care for as following from the existence of need and helplessness, we should care for ideas, institutions, values and objects, and practices that would diminish such needs" (p. 65). For Manning, this requires attention to individual action and also collective political responses to human needs. This comports well with social work's dual commitments to "individual well-being in a social context and the well-being of society" (NASW Code of Ethics, 1996, p. 1). Additionally, this chapter argues that the resources of the profession can do practical work for a public ethic of care.

Long-term care is an important subject within the field of aging, and it is a critical and important practice field for social workers. As noted in Chapter One, however, the focus here is not on social work roles, tasks, and interventions in long-term care but rather on the societal and organizational contexts in which long-term care is conceptualized and delivered. Even though the focus of this dissertation is not on direct practice issues in long-term care, it seems prudent to conclude by addressing direct practice issues and consider how the profession might be shaped and informed by a public ethic of care. An overview of social work's involvement in long-term care is addressed first; a discussion of several social work professional foundation areas - -specifically, policy, research, and practice - - and a public ethic of care follow.

Social work and Long-Term Care

The demand for social work services in the field of aging is predicted to increase through the year 2020 (Klein, 1998). U.S. News and World Report (1995) reports that gerontological social work is one of the fastest growing job markets in the United States. Green, Barusch, and Connelly (1990) predict the need for 60,000 to 70,000 gerontologically trained social workers within the next 20 years (as cited in Strengthening Aging, 1999). Scharlack (1997) recommends that schools of social work train a minimum of 5000 new social workers with specialized expertise in gerontological social work each year. The Bureau of Labor Statistics predicts the need for a 47.4 percent increase of social workers in health care settings between 1998 and 2008 (2000-2001). Although health care is broader than the field of aging or long-term care, given that the majority of social workers in health care settings serve predominately older persons, this increase will require additional gerontologically-trained practitioners (Damron-Rodriguez and Lubben, 1997).

While precise numbers are unavailable, it appears that social workers currently represent only a small segment of workers in aging and in long-term care settings. Only 4.2 percent of NASW members identify aging as their primary field of practice (Gibelman & Schervish, 1997). Within the health services industry, the Bureau of Labor Statistics reports that social workers constitute 1.5 percent of all professionals (157,000), third after registered nurses (29.5 percent) and physicians (16 percent) (2000 – 2001).[1] In home care, Goode (2000) reports there are about 6000 full-time equivalent social workers; they constitute less than two percent of the workforce represented by social workers, nurses, and nurse aides. Estimates of social workers employed in nursing homes are difficult to make. Under OBRA 1987, Medicare/Medicaid certified facilities with more than 120 beds must maintain a full-time "qualified" social worker. "Qualified" is operationalized as a worker who has either a BSW or a BA in a human services field.[2] Facilities with less than 120 beds are not required to hire a full-time social worker; they may have a part-time or contractual worker.

Currently a gap exists between the growing need for gerontologically-trained social workers and the state of social work education in this area. Sixty-two percent

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[1] The health services industry includes settings such as hospitals, nursing and personal care facilities, physicians' offices and clinics, home health care services, dentists' offices, other health care practitioners' offices, other health and allied services not classified elsewhere (such as outpatient drug rehabilitation centers), and medical and dental laboratories.

of National Association of SocialWork (NASW) members state the need for gerontological knowledge in their current practice (Peterson and Wendt, 1990). Only 10 percent of social work students have taken a course in aging (Damron-Rodriguez, Villa et al, 1996) and less than five percent of graduating MSW students have taken a course in gerontological social work (Klein, 1998). Eighty percent of BSW programs offer no course in aging (Lubben, Damron-Rodriguez, and Beck, 1992); only 39 percent of MSW programs offer concentrations in aging (Schneider, Kropf, and Kisor, 2000).

In spite of disparities between the number of actual and needed gerontological social workers, and the gaps in education, the social work profession has responded and continues to respond in varied ways to address the increasingly obvious issues raised by an aging population. The Association for Gerontological Education in Social Work (AGE-SW), consisting primarily of social work educators, has been active in developing courses and curricula in gerontology since the early 1980s and has extended its leadership and assistance to all social workers in the aging field (AGEnda, 2000). An emphasis on geriatric education and training came from the 1995 White House Conference on Aging. Here it was emphasized that social work education ought to include a careful study of policy issues that affect older adults as well as an understanding of the long-term care service continuum and related financing and access issues (Damron-Rodriguez and Lubben, 1997; Saltz, 1997). In 1998, the *A National Agenda for Geriatric Education* was issued (Klein); this report

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[2] The latter degree is questioned by many as sufficient for the work at hand, and is not recognized by the profession as a legitimate degree for practicing social work (Schneider, Kropf, and Kisor, 2000; Tirrito, 1996)

promoted the integration of aging content into all accredited social work programs, the preparation of social workers to practice in interdisciplinary settings, the provision of post-graduate education in gerontology, and the development of leadership and research centers of excellence at key universities with established geriatric resources.

Also in 1998, the John A. Hartford Foundation committed an initial $5.5 million for four years to the professional education of social workers in gerontology. Known as SAGE- -Strengthening Aging and Gerontology Education for Social Work- -this project targeted developing geriatric field practica for MSW students, establishing a geriatric social work faculty scholars program, and developing standards and best practices for undergraduate and graduate social work education. As part of this project, a survey was conducted in 2000 by SAGE and the Council on Social Work Education regarding needed gerontological competencies for all social workers, and needed competencies for advanced practitioners or specialists in aging. The basic aging competencies needed by all social workers included:

1. Assess one's own values and biases regarding aging, death, and dying.
2. Educate self to dispel the major myths about aging.
3. Accept, respect, and recognize the right and need of older adults to make their own choices and decisions about their lives within the context of the law and safety concerns.
4. Normal physical, psychological, and social changes in later life.
5. Respect and address cultural, spiritual, and ethnic needs and beliefs of older adults and family members.

6. The diversity of attitudes toward aging, mental illness, and family roles.
7. The influence of aging on family dynamics.
8. Use social work case management skills. . . to link elders and their families to resources and services.
9. Gather information regarding social history such as: social functioning, primary and secondary social supports, social activity level, social skills, financial status, cultural background, and social involvement.
10. Identify ethical and professional boundary issues that commonly arise in work with older adults and their care-givers, such as client self-determination, end-of-life decisions, family conflicts, and guardianship (SAGE-SW, Fall 2000, p. 1-2).

Competencies needed by advanced practitioners or specialists included:

1. Conduct clinical interventions for mental health and cognitive impairment issues in older adults.
2. Assess for dementia, delirium, and depression in older adults
3. Basic pharmacology and the interaction of medications affecting the elderly.
4. Adapt psychoeducational approaches to work with older adults.
5. Assess short-term memory, coping history, changes in socialization patterns, behavior, and appropriateness of mood and affect in relation to life-events of those who are aging.

6. Demonstrate knowledge and ability to use relevant diagnostic classifications such as the DSM-IV for use with older persons.
7. Identify legal issues for older adults, including advanced directive, living wills, powers-of-attorney, wills, guardianship, and Do-Not-Resuscitate (DNR) orders.
8. Develop strategies to address service fragmentation and barriers within the aging services delivery system.
9. Identify mental disorders and mental health needs in older adults.
10. Demonstrate knowledge about policies, regulations and programs for older adults in health, mental health, and long-term care[3] (SAGE-SW, Fall 2000, p. 2).

These findings are being used to develop resources and materials for aging competency integration into existing curricula as well as developing, when feasible, specific social work courses on aging.

In addition to educational initiatives in the field of aging, the social work profession has increased its public visibility in the field of aging. In 1998, the NASW established, for the first time, a specialty Section on Aging, projecting new and changing priorities in the need for gerontologically-trained practitioners (NASW

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[3] The survey sampled 2,400 social work practitioners and academics, both with and without aging interest. The sample was drawn from social workers who have taken one of the four licensing examinations from the American Association of State Social Work Boards, NASW members who indicated their primary field of practice was aging, individual members of CSWE, and members of AGE-SW. The survey was constructed after completing a literature review and consultation with expert researchers and practitioners. For a complete listing of all 65 competencies, see the CSWE/SAGE-SW website at www.cswe.org/sage-sw/

News, 1998). Social worker Jeannette Takamura became the Assistant Secretary for Aging at the U.S. Department of Health and Human Services in 1998 and in 1999, the United Nations observed the International Year of Older Persons (IYOP); social workers Rose Dobrof and Terry Hokenstad co-chaired the U.S. observation of the UN celebration. Social workers are also leaders in several of the most prominent interdisciplinary gerontological organizations in the nation, including the Gerontological Society of American, the American Society on Aging, and the National Council on Aging, the American Association of Retired Persons, and several others. Also, NASW journals (*Health and Social Work*, *Social Work*, and *Social Work Research*) are receiving an increasing number of high quality manuscripts from persons who publish regularly in other prestigious journals, such as *The Gerontologist; the* social work journals are also drawing from social work practitioners interested in aging and improving service delivery to older adults (Keigher, Fortune, and Witkin, 2000).

The social work profession also directs significant attention specifically to long-term care. In terms of standards, NASW's most visible policy statement regarding long-term care is put forth in *Social Work Speaks* (2000-2003). Here NASW recognizes that long-term care services are characterized by difficulties in access to care, eligibility and availability of appropriate services, and financing of care. Additionally, NASW recognizes that guiding principles for policy development and implementation are needed, as well as work in defining the ethical underpinnings of long-term care. In terms of reform, NASW recommends access to a variety of health and social services across a continuum of care; services should encompass "mental health, rehabilitation, nutrition, home- and community-based care services, . . . advocacy and elder rights protections, health promotion, volunteerism, and employment" (p. 212). The systems in which services are delivered should be diverse, and social work services should be integrated into all systems of care. In terms of eligibility for and availability of services, NASW recommends that biopsychosocial and cultural needs and related functional abilities be the basis for long-term care services in contrast to medical need only; availability of social work services should be connected to functional need not solely related to a medical diagnosis or the involvement of a physician. Care-givers should also be eligible for services. NASW recommends further that an adequate system of financing long-term care be developed; this should be part of a larger reform that provides universal, comprehensive health care coverage, including coverage for physical and mental health care and long-term care for all citizens. Finally, NASW recommends reform in quality of care. Quality of care can be furthered through consumer and family participation and choices about services and providers. Consumers and families, along with service providers, should be included in outcome evaluations that measure consumer satisfaction and quality of life issues. In addition to its formal policy statement on long-term care, NASW also sets standards and clinical indicators for social work in home health care and more generally in health care settings (NASW, 1987, 1995) as well as standards for social work services in long-term care facilities (1981) and clinical indicators for adequacy of services (1993).

The functions of social workers in long-term care settings are also a focus of study within the profession. In Medicare-funded home health care, social work roles are secondary; to be reimbursable, social work services must be prescribed by a physician or nurse, and must constitute direct, rather than indirect, service. Medicare standards for home health care agencies require that social work services be available to patients but do not require that patients see a social worker or that social workers be involved in design of the care plan.

Goode (2000), in a review of the literature on social work practice, noted five major areas of practice in home health care: assessment of social/emotional factors; counseling for future needs and assistance with decision-making, linking to community resources, short-term therapy, and intervention for high risk patients (abuse, neglect, suicide, lack of basic needs). Similarly, Egan and Kadushin (1999) found in terms of social work practice functions in home care a high degree of consensus regarding practice activities such as service coordination, assessment, and counseling, services previously identified as important to home health care (Fessler and Adams, 1985; Kerson and Michelson, 1995; Levande, Bowden, and Mollema, 1987; and Vincent and Davis, 1987). Additional functions of home care identified in Egan and Kadushin's study included patient advocacy and health education and, to a lesser extent, care planning and educating coworkers about social work. Egan and Kadushin also found that a majority of workers discussed ethical dilemmas with coworkers, and two-fifths did so regularly. The ethical issues raised most frequently included self-determination, concerns about advance directives, assessment of mental competence, and barriers to access of services. These concerns were similar to those raised in earlier studies of ethical issues in home care (Arras and Dubler, 1994; Callopy, 1988; Callopy, Dubler, and Zuckerman, 1990; Kane and Caplan, 1993; Robbins, 1996). In Egan's study, ethical concerns were raised more frequently in proprietary agencies than in non-profits, particularly in regard to access to services. Egan and Kadushin found that workers turned to co-workers rather than supervisors for support and expertise, raising the question as to whether workers found in their supervisors the necessary support and expertise to resolve difficult issues.

A number of social work functions are also identified within nursing home settings. Social workers assist in assessing appropriateness for and decision-making with potential residents and their families regarding the decision to enter a nursing home. Upon admission, social workers complete comprehensive assessments for residents, help orient them to the institution, and involved them in care planning if they wished for such involvement. Social workers continue to provide counseling and support in terms of adjustment, and assistance in planning for the future in terms of financial need and end-of-life care (Galambos, 1998). They further social functioning through various intervention strategies, participate in interdisciplinary case planning, and advocate for residents and for relevant policy and program changes (Stahlman and Kisor, 2000). Finally, nursing home social workers monitor the effect of government and organizational policies on residents' well-being, and assist in discharge planning (Cowle, 2000; NASW 1981; Vourlekis, Gelfand, and Greene, 1992).

A Public Ethic of Care in Long-Term Care, Social Work, and Policy

It is evident from this brief review of the connections between long-term care, the social work profession, and social work education, that direct practice issues emerge as central in the field of aging for social workers. Broader social and political conditions that shape the formation and delivery of long-term care are not the main focus of social workers' activities. Neysmith (1999) makes a similar observation. Although social workers are players in the policy arena, they typically do not set policy priorities; although they are charged with meeting basic needs, they seldom are able to determine resource allocations. The profession "is seldom an institutional force in defining public policy resource allocations even though individuals, and at time representatives from some arms of the profession, may enjoy the temporary privilege of walking the corridors of power" (p. 3).

Neysmith (1999) is well aware of the realities in which social workers in the field of aging practice, and her observation is not meant as an unkind criticism of practitioners. Yet she, and others, continue to challenge and encourage social workers to continue their dual focus on client systems and environments, linking client systems to social policy (Domanski, 1998; Schneider and Netting, 1999; Stuart, 1999).[4] Stuart argues that social work's persistent attention to social work's dual focus is precisely the unique and distinctive contribution that social work makes to American life. Similarly, Schneider and Netting argue that the dilemma between the "social" and the "psychological" - - between responsibility for addressing social

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[4] See Schneider and Netting (1999) and Stuart (1999) for succinct and interesting summaries of the significant achievements of social workers in influencing social policy.

issues and reform through policy influence and providing assistance to individuals - - is what actually defines the profession.

It is especially important for social workers not to walk out on their responsibilities to influence social policy in our current *modus operandi* of devolution, argue Schneider and Netting (1999). Although the data is inconclusive to date, Schneider and Netting point to a number of unsettling outcomes from the 1996 Personal Responsibility and Work Opportunity Reconciliation Act that should minimally give pause, and hopefully encourage the best of advocacy, to thoughtful practitioners about the political will of states to deal with persons of limited income and other marginalized groups in a caring and just manner. Their insights can be extended to long-term care as well.

The long-term care needs of the very poor frail elderly and their informal care-givers are already embroiled in Medicaid politics between federal and state governments, as discussed earlier. Particularly worrisome in long-term care is the push toward market solutions of purchasing long-term care insurance and continued defaulting of increased family care for frail elders. While there is much to commend, for instance, in the recommendations of Michigan's Long-Term Care Work Group, the theme of individual personal responsibility for one's long-term care needs, operationalized in large part through the purchase of private long-term care insurance, is infused throughout the report (Michigan Department of Community Health, 2000).[5]

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[5] In addition to purchasing private long-term care as part of personal responsibility, the workgroup's recommendations also include recommendations for further supports for informal care-givers so that they can continue to do their carework for as long as possible. As discussed earlier, this is good and bad news. Certainly informal care-givers need support; however these responsibilities fall heavily to women.

From the perspective of a public ethic of care, this is troublesome in several ways.[6] Private long-term care insurance relies on faulty assumptions about human nature, constructing persons as essentially self-sufficient and independent, and understands citizens to be wage-earners only; this financing mechanism does not recognize care as a foundational social value owed to all citizens as citizens and care remains invisible as a worthy public goal. Furthermore, those who have spent their lives caring for others (paid or unpaid) will likely be unable to afford private long-term care insurance. Additional invidious inequalities are reproduced as those who are healthy and wealthy can purchase more affordable long-term care insurance while risk pools become more segregated, with higher premiums and/or less coverage for the more frail (Moon, Nichols, and Wall, 1996; Nichols, Moon, and Wall, 1996). These consequences of more deeply segregated risk pools and the perpetuation of two-tiered systems of care do not easily become matters for public concern; hence, it is imperative that social workers, who see first-hand how policies shape service-delivery and care-giving to frail elders, continue to develop expertise in bridging policy and practice.

Social workers must continue to hone their policy skills on behalf of paid care-givers as well. Concern for employment issues and being able to earn a living wage date back to the Settlement House and Charity Organization Society era within the profession. In 1924, Mary Van Kleeck, reflecting on the professions' progress in terms of setting *Social Standards for Industry* since 1912, argued that social workers

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Furthermore, the recommendations are divorced from a public discussion about how such expectations should be sorted.

[6] These concerns were developed more fully in Chapter Six.

of the 1920s needed ongoing contact with working people to develop an industrial program for the future: "Whatever testimony we have to give gets its validity from actual human intercourse with those who working in industry" (1924, p. 372).[7] Her words ring true today. Social workers in long-term care setting today, who wish to be true to the profession's historical roots, must be able advocates for living wages for those who bear the heaviest burdens of carework; social workers' location in the interstices between frail elders, family members, careworkers, and administrators enables them to be credible witnesses in advocating for policy change. An immediate and concrete arena in which to advocate here is again in terms of the recommendations of the Michigan's Long-Term Care Work Group (2000). While the work group offers several thoughtful recommendations regarding paid long-term care-givers and what needs to happen to ensure adequate staffing levels, attention to reform of the wage structure of these workers is sadly missing.

A public ethic of care can do much to further social work commitments in the policy arena. When care is moved to a visible place in the public arena, the goals and strategies of social work's century old commitments find a receptive framework on which to hang its claims. Advocating for the disenfranchised, providing individualized services to meet unique needs in a respectful manner mindful of cultural and ethnic differences, enhancing and restoring relationships between people and groups, and pursuing social justice and meaningful opportunities for participation

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[7] Van Kleeck was referring to the report of the Committee on Standards of Living and Labor to the 1912 National Conference of Charities and Correction entitled, "Social Standards for the Industry." In addition to wages, the committee was concerned with hours of work, safety and health in employment, housing, term of working life, and unemployment insurance (Lovejoy, 1912).

in the deliberations that affect one's life are central values espoused by the social work profession (NASW Code of Ethics, 1996). These accord well with key facets of a public ethic of care as discussed earlier.

Reciprocally, the knowledge, skills, and values of the social work profession can further a public ethic of care. As a profession that works closely with people, social work's voice in the public square about what frail elders and care-givers need is required to develop public policy congruent with an ethic of care. The profession has both century-old strategies of advocacy for shaping the development of public policy and curricular structures in place that require competence in policy arenas. The profession has within it already the resources to operationalize a public ethic of care in long-term care. In short, the conceptual and theoretical work of a public ethic of care that certain political theorists, philosophers, and sociologists propose accords further legitimacy to the values social work embraces in its policy decisions; social work in turn provides the practical strategies needed to operationalize a public ethic of care.

A Public Ethic of Care in Long-Term Care and Social Work Research

Neysmith (1999) argues that although social workers occasionally occupy places of power, these arenas are unlikely to produce research and practice theory useful to the lives of those who experience gender, class, and race inequities as they age. Such research will come from those closest to care-giving experiences, and this research has the potential, says Neysmith, to further analyze the interaction between the personal and political, opening up new research possibilities. Research questions defined and generated by those closest to the care-giving experience are congruent with an ethic of care. It is also well-suited to the direct practice location of many social work practitioners, and ideally should accord well with the research knowledge and skills with which practitioners enter the field.

A decade ago, Johnson and Barer (1990), in a critique of the care-giving literature in gerontology, noted as a major methodological problem that recipients of care are rarely interviewed. In contrast to a plethora of research on long-term care trends for funding and delivery of services, little is known about elderly people's perceptions of their needs for long-term care and what they value by way of long-term care. Instead, as historically has been the case, the discourse of long-term care in the professional literature is frequently framed in the language of economics and motivated by efficiency, cost-containment, and costsavings. Studies that begin from the experiences of frail elders are limited. From the perspective of a public ethic of care, which makes meeting needs a starting point, this is unacceptable.

Little seems to have changed in the 1990s. Brief observations of the type of major articles and practice concept articles published in *The Gerontologist* from 1990 through 1999 (n = 914) identified only 12 articles (1.3 percent) addressing elders' preferences regarding some dimension of long-term care.[8] Four of the articles

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[8] The use of the word "observations" is intentional; a rigorous and empirically-designed content analysis of the gerontological literature is beyond the scope of this project. Rather, abstracts of each article were read to determine article content, and in particular, to determine from whose perspective the study began. The abstracts that explicitly worked from elder's perceptions were culled. Of course, one would hope that articles that evaluated, for instance, particular interventions or programs may well have been working from stated needs of elders but because this was not clearly articulated in the abstract, it is not reflected in this count. Such articles, additionally, tend to evaluate interventions and programs in terms of numerous variables, and when considering the effects of programs on elders, often use pre-selected categories identified by experts, not clients, to solicit elder feedback. I chose to use *The*

considered the attitudes of the elderly toward life-prolonging treatments (Berger and Majerovitz, 1998; Cohen-Mansfield, Droge, and Billig, 1992; Michelson, Mulvihill, Hsu, and Olson, 1991; Mutran, Danis, Bratton, Sudha, and Hanson, 1997), two addressed elders' preferences for care settings (Keysor, Desai, and Mutran, 1999; Peek, Coward, Lee, and Zsemblik, 1997), two considered elders' values in regard to various long-term care decisions (Degenholtz, Kane, and Kivnick, 1997; McCullough, Wilson, Teasdale, Kolpakchi, and Skelly, 1993). The remaining four articles were a sampling of assorted topics such as assessing elders' perceptions about the salience of loss in their lives (O'Connor, 1994), elders' experiences with trying to remain as independent as possible for as long as possible in the community (Pallett-Hehn and Lucas, 1994), perspectives of elderly Alzheimer's patients (Cotrell and Schulz, 1993), and an anthropological investigation of elderly death in the intensive care units and the relationship of these to the notion of "death with dignity" (Kaufman, 1998).

Moving closer to the field of social work, the *Journal of Gerontological Social Work* was similarly examined. It was thought that a journal specific to the field of social work in contrast to the interdisciplinary focus of *The Gerontologist* might focus more intentionally upon the perceived needs of frail elders as presented by this population, given social work's historic commitment to individualized service provision and its mantra of "beginning where the client is at." From 1991 to 1999, 376 full-length articles were published in the *Journal of Gerontological Social Work*;

Gerontologist to review because it is a well-respected (with good reason) journal that has an interdisciplinary focus as reflected in its statement of purpose: "[*The* only five of these (1.3 percent) addressed elders' preferences regarding some dimension of aging and long-term care.[9] In short, the social work profession's gerontological research also has not focused in a sustained way on elders' perceived needs as a starting point for program and policy development but has, in many ways, mirrored the research agenda of gerontologists, social scientists, scientists, and economists at large. Furthermore, various searches in social science and health care databases identified only a handful of articles (most of which are mentioned above) that explicitly and intentionally turned their focus to understanding elders' perceptions of long-term care needs.[10]

This informal investigation into what the gerontological literature studies is reinforced by Bradly, Bogardus, et al. (2000). They assert that evaluative outcomes of outpatient geriatric assessment focus on a rather limited set of outcomes related to functioning, service utilization, and costs. Their study, they claim, is the first to focus on identifying important goals for care as identified by patients and family care-givers. The construction of their questionnaire emerges from qualitative studies of what patients and care-givers desire. They suggest further, in the context of discussing their findings, that perhaps the focus of outcomes studies should be on

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Gerontologist] provides a venue for scholarly research as it reflects and informs the broad community of disciplines and professions concerned with human aging."

[9] See Burack-Weiss (1991) for elder's reactions to vision loss; see Mead (1991) and Weisburg (1991) for nursing home experiences; see Patterson, Baker, and Maeck (1993) for preferences regarding the use of durable powers of attorney for health care decisions; see Furstenberg (1994) for understanding client assumptions about age.

[10] Data base searches included Medline, SocioAbs, and Sociological Abstracts using advanced search strategies and key works of long-term care, elder needs, elder preferences, and elder values.

whether patient goals are met, regardless of what those goals are.[11] Although their discussion is not presented in the context of an ethic of care, such an orientation is congruent with an ethic of care given the authors' commitments to working within the framework of elders' perceptions of their perceived needs.

This discussion is not intended to suggest that empirical research in the field of long-term care is unimportant or unnecessary. Indeed, effective care work must be performed competently, and because public dollars fund part of long-term care, an ethical responsibility exists to make certain that these dollars are spent wisely and effectively. Empirical research, however, does not always follow some of our most compelling and bewildering social problems. The problem of how best to care about frail elders is not simply, or even principally, a technical or economic problem that will be solved in some magic bullet research study. It is first, and primarily, a moral problem whose solution is only furthered by a public commitment to care about those among us who can no longer care for themselves. Polivka (1998) emphasizes that "the science of long-term care will not do the work of the moral imagination in the development of a long-term-care system that is fundamentally responsive to what the frail elderly and their care-givers want and deserve" (p. 21). For this, we need a collective change of heart that is "fundamentally dependent on the creation of a clear moral vision for long-term care" (p. 22).

In the absence of a shared public moral vision for caring about frail elders, research will continue to respond to only part of the problem of long-term care, that

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[11] Of course, we need mechanisms by which to determine what goals are reasonable and what needs can be met. This was discussed earlier.

is, those dimensions of it that can be subjected to an empiricist model of science. The iatrogenic effects of this narrower focus are of concern to those who espouse an ethic of care, and should be of particular concern to the social work profession. Elderly persons are turned into subjects - - "to be turned this way and that, to be inspected and analyzed" - - and reduced to objects of investigation (Glanz and Neikrug, 1997, p. 823). The roles of current and future elderly citizens in determining how we should care about each other is subsumed by an empiricist model of science which locates the power for defining research questions with the experts and often does not allow for a "fundamental valuing of clients' own knowledge and experience" (Weick, 1993, p. 16).

From both a social work perspective and a public ethic of care, this way of conducting research is limited; social work in tandem with a public ethic of care opens up and legitimizes other research questions, alerting thoughtful practitioners to those important areas of people's lives overlooked by an empiricist model of science, and other methodologies, such as qualitative and ethnographic studies.

A Public Ethic of Care in Long-Term Care and Social Work Practice Models

A public ethic of care, with its commitment to moving care to a central location in the public arena alongside cherished values of liberty and equality, also moves the goals of the profession more centrally to the public square, giving policy advocates the conceptual foundation needed to more forcefully and legitimately make their claims regarding the right to give and receive good care. A public ethic of care, with its starting point in meeting the needs of frail elders, opens up and affirms research questions and strategies that take seriously the expertise of those most closely involved in carework. Social workers, given their academic and field training, and their closeness to those in the care-giving situations, are particularly equipped to operationalize a public ethic of care. The same kind of reciprocity between a public ethic of care and policy/research agendas potentially exists between a public ethic of care and certain social work practice models, particularly in the concrete phases of care-giving and care-receiving.

Social work is uniquely positioned to respond to the multitude of everyday decisions and experiences that need to be addressed in long-term care. The profession's historic emphases upon self-determination, individualized care, understanding persons in relation to their environments, diversity-competent practice, skilled communication, and empowerment is well-suited to develop practice models of care that emerge from the needs of elders as they perceive such needs. Unfortunately, the profession's commitment to these emphases is sometimes little more than "lip-service" because it relies upon traditional problem-solving methodologies grounded in and heavily influenced by assumptions of the medical model, one of the dominant discourses of long-term care.[12] Often the unique

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[12] Traditional problem solving methodologies include the stages of problem description, professional diagnosis to determine etiology, intervention based upon professional assessment, and evaluation. That the profession relies heavily on problem-solving methodologies grounded in medical models is not an argument that can be fully developed here. Interested readers will note that conceptions of generalist social work practice for which B.S.W.s are prepared, are often operationalized in terms of problems (see, for instance, Kirst-Ashman and Hull, 1993; McMahon, 1996; Schatz, Jenkins, and Shaefor, 1990). Beyond conceptualizations of generalist practice, a problem-solving focus and methodology historically and currently prevails in the social work literature (see, for instance, Compton and Galaway, 1989; Johnson, 1989; Levy, 1967; Perlman, 1957; Pincus and Minahan, 1973; Richmond, 1917). Although these models differ somewhat from each other, they are alike in that they share a similar structure - - assessment followed by

contributions of the social work profession are overshadowed by diagnosis and assessment of problems.

While problem-solving methodologies are well-suited to the curative goals of scientific medicine, the concerns presented by care-givers and care-receivers in a long-term care context are more extensive than the goals of curing and include significant psychosocial concerns (Greene and Adelman, 1996; McCormick, Inui, and Roter, 1996). The resolution of such concerns are mediated by a host of variables, including cultural, ethnic, social class, moral, religious, and demographic factors. Quality long-term care does not present the kind of issues best understood by problem-solving methodologies requiring convergent thinking oriented toward medical models of restoring one to health. Rather, divergent thinking and reasoning, which recognizes that there is not one "right" answer and is willing to consider several perspectives in searching for decent solutions within clients' frames of reference, is more appropriate to the experiences of long-term care-givers and care-receivers (Rappaport, 1981). Recognizing this, as well as the fact that many decisions that must be made within and about long-term care are emotionally difficult, intensely personal, and not easily captured by predictive variables, social workers in many settings, particularly during the last decade, have come to challenge the usefulness of applying a scientifically-based medical model of problem-solving for psychosocial

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treatment, premised on the assumption that there are objectively real problems logically connected to solutions - - and rely on scientific expertise as the basis of helping.

issues. As an alternative to problem-solving models, ways of working with people grounded in social constructionist orientations have emerged.[13]

Solution-focused interviewing, one of several practice models grounded in social constructionism, is paradigmatically distinct from problem-solving methodologies and reflective of divergent thinking (Berg and De Jong, 1996).[14, 15] Social constructionism and solution-focused interviewing strategies both posit the social construction of reality and emphasize that change occurs through the discovery of new meanings. Both emphasize the importance of language as the medium through which personal meanings are expressed; consequently the language that clients use to describe their experiences is accorded great attention and respect. Both emphasize the legitimacy of contextual knowledge and hence take seriously the expertise that participants bring to the discussion. Both emphasize a collaborative posture and are suspicious, given their misgivings about scientifically acquired knowledge, of those "experts" who try to categorize and solve problems. Finally, both social constructionism and solution-focused interviewing strategies emphasize reflexivity. Social constructionists argue that reflexivity is tied to people's tendency

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[13] A complete analysis of this shift is beyond the intent of this chapter. See, for instance, Cantwell and Holmes, 1994; De Jong and Berg, 1998; Franklin, 1995; Gergen, 1985; Goolishian and Anderson, 1991; Hoffman, 1990; Rappaport, 1981; White and Epston, 1990.

[14] The connections between social constructionism and solution-focused interviewing are interesting and complex, and stated only summarily here. See Berg and De Jong (1996) for a more complete discussion.

[15] Solution-focused interviewing strategies represent but one operationalization of social constructionism in terms of working with people. These particular strategies emerged out of the work of Steve de Shazer, Insoo Kim Berg, and their colleagues at the Brief Family Therapy Center in Milwaukee, Wisconsin. Its assumptions, structure, and procedures were developed inductively during approximately 20 years of disciplined observation of sessions with clients.

to reshape and expand their meanings; through their abilities to abstract and use language, people can "climb out" of themselves and reflect on their situation, perhaps opening up new meanings and possibilities for change. Solution-focused interviewing, through the use of relationship questions, ask people to draw upon their capacities for reflexivity by considering their lives through the perceptions of others.

Although a thorough description of solution-focused interviewing strategies is beyond the intent of this chapter, some description of interviewing questions is necessary to support the claim that these strategies accord well with both an ethic of care and social work commitments. Broadly, solution-focused questions help persons create well-formed goals within their own frames of reference and develop solutions out of existing strengths and successes (de Shazer, 1985). Embedded in these two activities are questions which take into account key relationships in one's life, questions for assessing hopefulness, motivation, and outcomes, questions which assess existing successful coping strategies, and questions which amplify previous answers to earlier responses.

Solution-focused conversations often begin with asking persons, "How can I be useful to you?" What follows is often a description of problems. Rather than exploring the who, what, where, when, and why of these concerns in detail, solution-focused interviewers respectfully turn the conversation toward developing goals, listening carefully for who and what is important to a person, and what that person wants different in his/her life. A question such as "When things are better for you, what will be different?," invites persons to think about future possibilities and what they would like different when current problems do not exist.[16]

This conversation is supported by a number of explicit interviewing questions designed to help clients develop a different and more positive picture or story that is important to them. *Amplifications questions* such as, "When things are better for you, what will you notice is different in your life?," "What will your partner (or child, care-giver, etc) notice about you that tells her things are better for you?" or "What tells you this is best for you?" round out contextually the picture of what persons want different in their lives. *Relationship questions* bring in the perceptions of important others: "What might your daughter say about your hope that you can return to your home?" What will your partner (or child, care-giver, etc) notice about you that tells her things are better for you?" can be explored, followed by further amplification and/or relationship questions. *Exception questions* seek out "past experiences in a client's life when the problem might reasonably have been expected to occur but somehow did not" (De Jong and Berg, 1998, p. 95). Details of the exception - - the who, what, where, and when of these times - - are useful to exploring strengths and capacities: "Are there days when you are more able to take care of

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[16] The hallmark question of solution-focused interviewing around goal-development is the miracle question: "Suppose that while you are sleeping tonight, a miracle happens. The miracle is that the problem that brought you here is solved. However, because you are sleeping, you don't know the miracle has happened. So, when you wake up tomorrow morning, what will be different that will tell that a miracle has happened and the problem which brought you here is solved. . . What else will you notice?" (de Shazer, 1985, p. 5). Follow-up questions are used to develop a miracle picture that is contextualized, a beginning step, realistic, and measurable and concrete. In my professional experience with older adults, I have not found this question particularly useful.

yourself at home? . . . tell me about those days? . . . what is different about those times?" *Coping questions* are useful to use when no good solutions or exceptions are apparent, or when persons are overwhelmed with the condition of their lives. Examples of coping questions include: "What keeps you going,?" "How do you get through days that are long and lonely,?" "How have you learned to let other people help you with bathing and dressing?" These questions uncover additional strengths and capacities, identify cognitive and conceptual shifts about what is important to people, and highlight the kinds of things and people that continue to provide meaning in dire circumstances. *Scaling questions* assess persons' perceptions of many things, including "self-esteem, pre-session change, self-confidence, investment in change, willingness to work hard to bring about desired changes, prioritizing of problems to be solved, perception of hopefulness, and evaluation of progress" (Berg, 1994, pp. 102 – 103). Persons are asked to put their observations on a scale from one to ten, where one stands for the worst possible scenario and ten represents the best possible scenario. A nursing home resident, for instance, might be asked to scale her perceptions of her new living situation. Her answer of "three," for instance, can be followed up in several ways: "What tells you that this place is a three and not a one?" "What would need to be different for you to say this place is a four?" "What would this place need to be like for you to say it is a ten?" Mining these questions can lead to useful suggestions for care plans and care-giving that is individually-suited for a given resident, regardless of gender, age, social class, or other variables typically difficult to predict in terms of outcomes.

Solution-focused conversations grounded in social constructionism are a good fit with an ethic of care as it is operationalized in care-giving and care-receiving. These interviewing strategies recognize that our selves are not pre-formed selves, but are shaped and changed through interactions with others. These interviewing strategies affirm the contextual knowledge acquired through lived experience, and also recognize the centrality of relationships and their importance in decision-making.

Solution-focused interviewing strategies are congruent not only with an ethic care but also with social work practice commitments.[17] They support an approach to working with people and communities from a posture of strength, rather than a narrow focus on problems.[18] They offer a way to work carefully and respectfully within clients' diverse frames of reference to clarify what it is that people want different in their lives and how they wish for change to occur. They offer mechanisms by which goals and decisions can be considered, mindful of the effects

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[17] Solution-focused interviewing as an approach to helping people is used widely around the world in diverse practice settings such as family services, mental health, public social services, child welfare, prisons and residential settings, schools, and hospitals. In Michigan, this approach is being integrated into child protective service work, and has already made inroads into determining eligibility for public social services. As a resource for practitioners, solution-focused interviewing strategies are taught in numerous schools of social work as well as graduate programs in psychology and counseling. There is at least one study being conducted with medical students and physicians at the University of Wisconsin Medical School (Milwaukee Campus) to determine how training in solution-focused interviewing can enhance communication between patients and physicians (G. Miller, personal communication, February, 1999).

[18] The assumptions of a strengths perspective in social work are developed most fully by Dennis Saleeby (1997). In short, Saleeby argues that despite life's struggles, all people possess strengths that can be marshaled to improve the quality of their lives. Practitioners must respect those strengths and the directions in which clients wish to apply them. Discovering strengths requires collaboration and cooperative exploration between clients and practitioners. Expert practitioners do not have the last word on what clients need to improve their lives.

of such choices upon people to whom they are connected via chosen or unchosen relationships. They offer a way to evaluate the outcomes of interventions in light of what clients say is important to them.

Comparative outcome studies using solution-focused interviewing strategies in clinical contexts indicate that such interviews take no more time than traditional interview times of 50 minutes per session. The number of total visits between practitioner and client are significantly lower using solution-focused interviewing strategies.[19] Final client satisfaction with solution-focused interviewing services exceeds satisfaction with problem-solving interviews (De Jong and Berg, 1998).[20] Gingerich and Eisengart's (2000) literature review identifies all controlled studies of solution-focused therapy conducted through 1999 (n = 15).[21] Five of these studies were well-controlled and all indicated positive outcomes.[22] The remaining ten studies, which were classified as moderately or poorly controlled, were consistent with a hypothesis of solution-focused effectiveness. The authors conclude that the 15 studies reviewed provide promising evidence of the effectiveness of solution focused intervention.

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[19] Mean of 2.9 visits in the Brief Family Therapy Study as contrasted to a mean of 13 in problem-solving interviews (De Jong and Berg, 1998; Lambert and Bergin, 1994).

[20] Seventy-seven percent of BFTC clients said they improved from their first to final session; comparatively, a 66 percent rate is reported by Lambert and Bergin (1994) for problem-solving therapies.

[21] Studies included in the literature review met the following criteria: they investigated solution focused therapy, employed some form of experimental control, assessed client behavior and functioning (in contrast to self-reports), and assessment occurred at the end of treatment or in a follow-up stage.

[22] The authors were guided in their critique of assessing empirical support for psychological treatments by the standards developed by the American Psychological Association (Task Force, 1995).

Solution-focused intervention strategies are useful not only in direct practice situations, where, for instance, the needs of frail elders and their families need to be sorted and addressed. They can do practical work as well in several areas previously mentioned.

Solution-focused intervention, when done correctly, is relentless in its pursuit of understanding individuals' frames of reference, the context in which they live their lives, the persons and things that create meaning, and the relationships that sustain life. This accords well with alternative ethical decision-making strategies addressed in Chapter Seven congruent with an ethic of care. Waymack (1998) reminds us that professionals should not presume ahead of time to know what ethical issues are most pressing to care-givers and care-receivers. He cautions, like Walker (1998) and Young (2000) that care-givers and care-receivers will not always have the conceptual vocabularies to articulate what is at stake for them. Solution-focused conversations promote the kind of dialogue affirmed in communicative and narrative ethics where ethical decisions are outcomes of a dialogue in which everyone, even those at the margins, are heard and respected. This kind of collaborative discourse enables ethical problems "to be refracted through multiple lenses, thus enriching the range of understanding and broadening sensitivity to its manifold consequences" (Gergen, 1994, p. 109). This stands in sharp contrast to principle-driven systems of ethical decision making which, for people who see themselves as "victims" of a social order run by privileged elites, appear more as "instruments of control than moral guides" (Witkin, 2000b, p. 199).

Solution-focused intervention can also be useful to developing and implementing a research agenda that takes seriously the needs and perceptions of frail elders and their families. Competent and systematic use of solution-focused interviewing strategies will yield a wealth of data about what care-givers and care-receivers value in long-term care, how the system works for them and against them, and their recommendations for change. These will be recommendations that take contextualized knowledge seriously and hold promise for developing Polivka's clear moral vision for long-term care (1998). Social work practitioners, given their unique social location in the structure and delivery of long-term care services will be well-positioned not only to collect data, but to reframe research questions based on their up-close knowledge of care-giving and care-receiving. Practitioners, by careful attention to what care-givers and care-receivers say is important, will notice what is present and what is missing from gerontological research (Witkin, 2000a); in this way, the profession's public duty to "make the invisible visible" can be furthered (Jennings, Callahan, and Wolf, 1987).

Similarly, policy development and implementation can be informed by thick descriptions emerging from solution-focused conversations of care-givers and care-receivers' experiences with long-term care. Gerontological social workers in direct practice settings are a crucial link to the organizational and public policy that shapes long-term care. Just as Settlement House and Charity Organization Society workers advocated for social change based on their close experiences with marginalized people, albeit from somewhat different philosophical postures, current practitioners must be vigilant about connecting the needs of frail elders and often exploited care-givers to the larger social, economic, and political climate. As Schneider and Netting (1999) argue, the essence of social work is to "connect the often-invisible struggles of individuals with the more public actions of decision makers in powerful positions" (p. 349). These authors are not hopeful, particularly in this era of the New Federalism, that a return to the "social" dimensions of social work will happen anytime soon or over an extended period of time. Consequently they urge an integrated approach to social work education, that among other things does not separate policy, research, and practice into separate tracks but instead brings into every class knowledge and skills about how policy shapes practice and practice shapes policy. Solution-focused conversations, grounded in social constructionism rather than stale problem-solving from pre-determined categories, offers possibilities for new ways of conceptualizing and implementing long-term care policy.

Finally, the resources of solution-focused conversations can be extended to democratic deliberation. It is not difficult to imagine various groups of stakeholders being asked to deliberate about their ideal vision of long-term care. Amplification questions will further a detailed, relational, and contextual picture of such care. Relationship questions will make visible what kinds of connections are important to support for care-givers and care-receivers, and what it is within relationships that sustains and restores meaning to old age. Exception questions will explore positive experiences with long-term care, uncovering what is useful and what it would take to provide more of such care.[23] Coping questions, like relationship and exception questions, will continue to mine for strengths, capacities, and resiliencies, as well as for supports that care-givers and care-receivers value. Scaling questions can assess deliberators' willingness to bring about change, evaluate and revise proposed policies and programs, and establish priorities. As in direct practice situations, the responses that emerge from such questions are firmly grounded in the concrete and particular experiences of participants; such responses are not limited by pre-determined expert organizational or conceptual categories of what long-term care should be.

Where We Go From Here

This chapter, in summary, attempts to tie together the usefulness of an ethic of care with the social work profession. As noted in Chapter One, the social work profession has not participated in larger discussions about the utility of an ethic of care, perhaps because of perceptions that the ethic confines care to private spheres or essentializes women as carers, or perhaps because social workers seldom have the time and/or interest to pursue such connections. Speculation is difficult, given that so little attention is paid to the discussion. This oversight is unfortunate, however. A public ethic of care provides a legitimating and sustaining framework on which basic social work values and commitments can operationalized. Reciprocally, the knowledge and skills that social workers already possess in the relationship between policy, research, and practice, along with practitioners unique location in direct care settings, allows social work to contribute to furthering a public ethic of care in concrete and practical ways.

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[23] PACE and Eden Alternative programs could be considered "exceptions" to problems in long-term care.

Given the apparent congruence between a public ethic of care and the commitments of the social work profession, social workers need to begin and continue the conversation about the usefulness of a public ethic of care in meeting human needs. This project makes an initial attempt to do this but the conversation must continue. Ideally such a conversation will spill over into professional conferences and journals, and if deemed legitimate, make its way into social work curricula and social work practice. Should we fail to have this conversation, we can be certain that social workers, while nevertheless working hard to fulfill the responsibilities of their work, will continue- -and perhaps shore up- -the status quo, leaving in place, for instance, the economic and medicalized way of caring for frail elders and leaving untouched the assumptions we make about people who need care.

Assuming a public ethic of care does make its way into social work's conceptual and theoretical underpinnings,[24] we will need to define new possibilities for research agendas. For instance, we will have before us the difficult task of operationalizing such notions as a social conception of the self or prioritization of relationships such that these can be more rigorously evaluated in care-giving and care-receiving situations. We will need to discriminate between competent and responsible care-giving practices in contrast to practices that are paternalistic or exploitive, determine how best to measure these, investigate what contributes to effective care-giving, and determine what counts as legitimate outcomes. We will need to study what kinds of deliberative settings best foster Young's vision for inclusiveness, political equality, reasonableness, and publicity. We will need to

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[24] This assumption is by no means a given.

develop, implement, and evaluate curricular strategies that address care competencies. And we will need to demonstrate empirically that what we bring to care situations as professionals is effective in meeting the needs of those who need care.

We will also need to broaden our categories of policy analysis to include explicit attention to a public ethic of care. New and existing policies should be evaluated against the benchmarks of a public ethic of care. For instance, the following kinds of questions ideally would become as common and accepted as policy questions about efficiency and cost-effectiveness: To what extent are those who stand to gain or lose by this policy involved in the development of it? What tells us that the voices of those who stand to gain or lose by this policy have been heard? To what extent does this policy understand persons as socially constituted, allow for contextual care practices, and honor meaningful relationships? To what extent does this policy recognize, affirm, and sustain the critical work that informal care-givers provide? To what extent does this policy further the ability of those who wish to do care work to do it competently and receive a living wage?

Finally, we will need to put our commitments to a public ethic of care into practice. We will need to refine practice models, such as those mentioned above, that work from assumptions radically different from traditional medical models of social work practice. These practice models will help us negotiate how those who need care can best receive it in ways that respect and value differences. These practice models can also provide a framework to use in our policy deliberations, our research agendas, and in the public square. Through small actions and persistent and willed commitments, we can begin to whittle away at prevailing norms and attitudes that, for instance, define care as a commodity or as a private issue, construct old age as a medical problem, hold out self-determining and independent adults as the norm for human experience, and perceive women as natural care-givers. In our intentional and persistent challenging of the status quo, whether it be in our work with families, within organizations, or in the public square, we can begin to cultivate a moral imagination for how best to care, to construct richer and more satisfying contexts for giving and receiving care, and to operationalize social work's long-standing, radical, and sorely-needed commitments.

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