



World Health Organization

# **ETHICAL CHOICES IN LONG-TERM CARE:**

# **WHAT DOES JUSTICE REQUIRE?**



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# Contents

ii	Acknowledgments .....	v
iii	Summary .....	vii
1	Overview .....	1
2	The Societal Perspective .....	5
3	The Role of the Family .....	11
4	Other Stakeholders .....	15
5	The Caregiving Relationship .....	17
6	Long-Term Care and Social Justice .....	21
7	The Way Forward .....	25
8	References .....	27

## APPENDICES

A. Long-Term Care and Social Justice: <i>A Challenge to Conventional Ideas of the Social Contract</i> Martha C. Nussbaum .....	31
B. Justice and Long-Term Care: <i>Need We Abandon Social Contract Theory?</i> A Reply to Nussbaum Norman Daniels .....	67
C. Can Contractualism Justify State-Supported Long-Term Care Politics? Or, <i>I'd Rather Be Some Mother's Child</i> A Reply to Nussbaum and Daniels Eva Feder Kittay .....	77
D. The African Perspective Dan O.C. Kaseje and Bavon Mpenda .....	85
E. List of Participants .....	87



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# Summary

Long-term care for people with chronic illnesses and disabilities presents an urgent challenge around the world. A recent WHO study estimates that in many developing countries the need will increase by as much as 400% in the coming decades (WHO, 2002a). Existing systems of care, which typically rely on unpaid family members, are not by themselves enough to meet growing demands. Though families will continue to play a central role, states must ensure that resources are available to address growing needs and that those resources are distributed efficiently and equitably.

A society invites a dialogue about how best to structure the ethical framework within which equitable, fair, rational, and transparent decisions about long-term care can be made when it asks: “What long-term care needs exist?” “What resources are available to provide them?” “What does justice require? The answers point the way towards systems that are responsible, accessible, efficient, and accountable, and that address the universe of human needs with dignity and respect.

The primary goal of this report is to identify some of the issues that need to be considered as those systems are designed. It reflects a consultation held over a two-day period at the University of Chicago in July, 2002 under the sponsorship of the World Health Organization’s Cross-Cluster Initiative on Long-Term Care. Philosophers, experts in public health and long-term care, and professionals knowledgeable about developing countries came together (see Participant List, page 87) to reflect on the moral basis of long-term care and to point the way forward. Their goal was not to reach consensus but rather to discuss relevant topics from many perspectives and to suggest an agenda for ethical considerations. Much more work in this arena lies ahead.

## THE SOCIETAL PERSPECTIVE

Putting respect for human dignity at the center of the social paradigm means accepting laws and social practices that protect the weak and vulnerable from domination, exploitation, or neglect. Society functions best as a harmonious whole when care that is consistent with respect for the individual is available to all, enabling those who have resources to enjoy their full benefits, while providing security to those who are less fortunate.

## ETHICAL CHOICES IN LONG-TERM CARE

From that perspective, societies should not be organized only with the idea of the “normal” person in mind, though they often are. A broader obligation to cater to the needs of those with some sort of limitation must also be recognized. Implied is that all people, including those with disabilities, have the right to function as fully as their condition permits, regardless of their starting place. The challenge then becomes removing any barriers that impede that goal.

**THE REALITY OF SCARCITY:** Only after acknowledging a fundamental ethical obligation to provide care can a society engage in a discussion of the necessary tradeoffs. In an environment of resource limitations, needs inevitably compete against one another as priorities are established and choices are made. Public deliberation can focus on cost thresholds, how best to define “reasonable” accommodation, and where extra costs outweigh the level of benefit—but the basic obligation for care must first be recognized.

**ISSUES OF GENDER:** Tradition, deeply embedded notions of a woman’s social worth and the value of her work, and the distribution of power within a society all explain, in part, why caregiving tasks have fallen disproportionately on women. Optimally, caregiving responsibilities should be shared without reference to gender. But if females continue to provide the bulk of the caregiving, limitations to their responsibility need to be considered in pursuit of justice.

**BIAS AND DISCRIMINATION:** In addition to a gender bias in the burden of caregiving, age bias may manifest itself in resource allocation decisions, in the legal framework, and in the way in which the social obligation to the ailing elderly is defined. There may likewise be a bias towards anyone who is disabled that colors the design of support systems, or that creates unethical distinctions between those whose disabilities can and can not be remedied. There is also in many societies a bias against isolated rural areas, with planning that fails to recognize their special needs and vulnerabilities.

**HEALTH REFORMS:** As health sector reforms are implemented, a minimum set of justice-based entitlements needs to be defined. An opportunity exists to incorporate some elements of long-term care into the package of services that Member States make available to all. Any universal package should be viewed as a starting point, however, not a limitation, so that the subset needs of smaller groups also receive consideration.

**WEIGHING PRODUCTIVITY:** Basic justice requires that respect for persons, not productive capacity, undergird decisions about who gets what. Only in the most extreme situations can capacity serve as the basis for allocating resources—for example, where the survival of other family members depends on a breadwinner’s access to care. Even then, it should be clearly understood that justice is not served. On the other hand, the goal of providing the resources

and opportunities individuals with disabilities need to reach optimal capacity can legitimately be considered in developing long-term care services.

**INSTITUTIONAL CARE:** The decision to place a family member in an institution should not be an act of desperation, as it so often is now, but a reasoned choice. A starting place for change is to be explicit that long-term care institutions exist within a community and are not exempt from community ethics and prevailing standards. Any societal commitment of resources to build institutions needs to be accompanied by a commitment to the basic human dignity of those who will use them.

## THE ROLE OF THE FAMILY

By recognizing that families are neither exclusively, nor necessarily, constructs of biology, but are also shaped by social conventions and cultural values, the distinction between what families and what society owe an individual needing care begins to blur. It is useful to question the premise that there is a certain, natural role for the family as first-line providers before building systems on that assumption. We also need to ask:

- What will families be expected to do, and for whom?
- Which members of the family are expected to shoulder these obligations, and why does the task fall to them?
- What supports can be provided to make the tasks easier?
- What limits should be set on the burdens imposed on family?

**SUPPORTING FAMILIES:** Mechanisms are needed to assess the strength and limitations of family caregivers, and to intervene with support and respite as needed. The call for community involvement, however, does not mean creating a bureaucracy to take over the caregiving role once family and friends reach the limits of what they can tolerate. Rather, opportunities for cooperation are needed along the way. Often something relatively modest—such as training, access to information, respite care, or opportunities to talk about concerns—is enough to sustain a caregiving relationship. Any outside involvement should enhance, rather than disrupt, the intimate relationships that exist between family caregivers and those to whom they provide care.

**PARTNERSHIPS WITHIN THE HEALTH CARE SYSTEM:** If the resources of the existing health care and social service systems are to be the first line of support for family-based care providers, communication between the acute care and long-term care systems needs to be improved. As well, partnerships between families and health care professionals need to be based on mutual respect and recognition of each party's unique strengths. Such partnerships are often challenging to build, however, because family concepts of intimacy,

## ETHICAL CHOICES IN LONG-TERM CARE

privacy, confidentiality, and decision-making often clash with the values of health care professionals.

## OTHER STAKEHOLDERS

**COMMUNITY RESOURCES:** An individual may be a member of many different formal and informal communities and organizations: for example, clans, traditional villages, funeral societies, women's groups, religious and professional associations, and friendship networks. Resources, training, and education may help to promote community involvement in long-term care. These civic groups can also push for a richer state response to long-term care needs and fill in service gaps where necessary, but they should not make it easy for government to abdicate responsibility.

**ROLE OF DEVELOPED COUNTRIES:** Much of the caregiving in wealthy and developed countries is being provided by care workers, nursing professionals, and others who have migrated from impoverished and developing countries. While these workers may experience economic benefit, they also create gaps in their own families and communities. Arguably, wealthy nations incur a debt in this exchange that somehow needs to be repaid. Likewise, it is reasonable to ask if the multinational corporations that depend on the natural and human resources in developing countries have a responsibility to fill the gaps in caregiving they help to create.

**INDIVIDUAL RESPONSIBILITY:** While the issue of personal responsibility for anticipating a more dependent future is a legitimate topic for discussion, emphasizing individual behavior can readily descend into victim blaming or become an excuse for avoiding social engagement. Moreover, it is legitimate to ask how much individuals can do for themselves in societies where they are challenged even to remain adequately nourished. Certain government decisions—such as whether to accept investments from tobacco companies or to fund primary care adequately—also influence health, thereby influencing the demand for long-term care.

## THE CAREGIVING RELATIONSHIP

A benchmark question should be asked when designing long-term care systems: Does each decision support and strengthen the foundational caregiving relationship? Understanding the complexities of that relationship begins with understanding the many ways in which the term “caregiver” is defined and the many different relationships to the care recipient that it implies. While the ethical obligations of caregivers have yet to be explored in depth, it is possible to offer some guidelines:

- Recipients of care and those providing it should have a voice in making decisions that affect them.
- Though certain cross-cultural differences may exist in defining abuse, there is no ethical justification for exploiting an individual's vulnerability.
- Anyone who needs long-term care should feel confident that those who provide it have the required knowledge, training, and skills.
- Equitable compensation, attractive working conditions, and access to training and advancement within the health care system all enhance the rewards of caregiving, as do structures that foster continuity and personal connections between the caregiver and recipient.
- States need to exercise responsible leadership and impose appropriate oversight to ensure the quality of the care offered to those who are most vulnerable.

## LONG-TERM CARE AND SOCIAL JUSTICE

WHO proposes that a much-needed consideration of ethical principles in long-term care begin with a description of the challenges of providing care to meet projected needs, and an assessment of the cultural values that underlie existing systems. That, in turn, encourages a look at whether existing approaches are sufficient, given future needs, and whether benefits, responsibilities, and burdens will be allocated fairly. Also important is an understanding of who will be asked to sacrifice what, and for the sake of whom.

WHO also seeks to introduce the ethical issues that arise in long-term care into ongoing efforts to fashion a coherent and appealing general theory of justice. Thus, exploring the ethical underpinnings of long-term care can guide societies as they decide how to allocate the benefits and burdens of social cooperation. The most fully articulated theories of justice have been products of philosophers and political theorists, and their enterprise is in vigorous and healthy development today. WHO's effort to interest these theorists in long-term care provides an important focus to some of the ethical debates currently underway; until now, this has been largely neglected.

To initiate this theoretical development, WHO has commissioned a philosophical paper by Professor Martha Nussbaum, of the University of Chicago's faculties of law and philosophy. Nussbaum's inquiry on the values underlying long-term

## ETHICAL CHOICES IN LONG-TERM CARE

care asks a series of searching questions about the adequacy of the social contract in addressing the needs of those who are dependent. Two commentaries—by Professor Norman Daniels of Harvard University and Professor Eva Kittay of the State University of New York at Stony Brook—probe and challenge components of Nussbaum’s analysis. These papers are included as an Appendix to this report.

## 1

# Overview

Long-term care for people with chronic illnesses and disabilities presents an urgent challenge around the world. A recent WHO study estimates that in many developing countries the need will increase by as much as 400% in the coming decades (WHO, 2002a).

This universal problem has been heightened by a combination of demographic and epidemiologic forces. Changes in social structure, which occur as the forces of modernization take hold, provide a partial explanation. The extreme poverty and uneven allocation of resources that are so widespread also influence the need for, and availability of, long-term care. At the same time, many families are having fewer children and as more young people migrate from rural to urban areas, and from poorer to richer countries, they may not be available to provide care. As women, who have traditionally been the givers of care, are pulled into the paid labour force by economic necessity or personal desire, they may be unable to continue providing those services. Their roles are changing in many societies and as they do, questions arise more often as to whether they can be fairly expected to sacrifice their own education and ambitions to become caregivers.

Much of the demand for long-term care comes from the aging population, with its chronic health challenges and increasing dependency. But the needs of other populations are also large and growing. Among the sources of additional pressure: the HIV/AIDS epidemic; changes in dietary habits and lifestyle in developing countries that contribute to a rise in diabetes, cardiovascular disease, and stroke; and economic development that increases automobile use, and therefore road injuries.

As demand for long-term care escalates, and the assumption that extended family networks can meet all the needs of their members erodes, existing systems of informal long-term care have come under great stress. Some have already begun to unravel. Who, then, will carry the burden?

Clearly, many families will continue to play a central role in providing long-term, home-based care. Usually, they want to take on this responsibility and in any case, no society can afford to look to the state to provide all of the long-term care that will be needed. But the obligation of caring for vulnerable populations can not rest with the family alone. The burden is too great and the

## ETHICAL CHOICES IN LONG-TERM CARE

resources are too few—not everyone is capable of providing care and not everyone has family members or friends available to do so. Nor can the marketplace, by itself, step in to fill the breach. As the limits of what has been done in the past become apparent, states must create alternatives that do not depend on care based exclusively on either affection or market principles.

The World Health Organization has urged governments to recognize that they are ultimately responsible for a country's health system. Though care may be provided by a combination of private, nonprofit, and public agencies, "government must be the prime mover," states a WHO report (WHO, 2000). Likewise, states are responsible for anticipating the needs associated with home-based, long-term care, which extend beyond the provision of health care services, and for ensuring that resources are available and are distributed efficiently and equitably.

It is impossible for anyone to predict his or her care needs. What is more certain is that all human beings have periods in their lives—whether in infancy, old age, or illness—when they must depend on others to provide care. Likewise, most women, as well as many men, will at some point step into the role of care provider.

Whether judged by the ethical standards within traditional societies, or by universal norms of equality and human rights, existing systems of allocating the burdens and benefits of caring for the chronically ill and disabled are unfair. Moreover, as needs increasingly outstrip resources, this inequity is likely to intensify. While traditional moralities are a basis for the obligations that most people accept to provide care for dependent family members and others in need, the contribution of deeply embedded cultural, ethical, and religious values to this unfairness also needs to be reexamined. Society invites a dialogue about how best to structure the ethical framework within which equitable, fair, rational, and transparent decisions can be made by asking: What long-term care needs exist? What resources are available to provide them? What does justice require? The answers, then, point the way towards long-term care that is responsible, accessible, efficient, and accountable, and that addresses the universe of human needs with dignity and respect.

To create a space for ethics in policy-making is to recognize the value of a deliberative process in which arguments are advanced and carefully evaluated. By examining and addressing ethical considerations and remaining open to policy revisions in light of criticism and experience, nations create a context in which their strategies can be more fully understood. That process opens each point of view to examination and criticism. The result is that all parties learn from one another and indefensible views can be identified and revised. Incorporating ethics into planning conveys a respect not only for the importance of weighing options and choosing among them, but also for the process of

doing so. The hoped-for result is a reasoned dialogue that illuminates questions of social justice from different angles.

There is no single solution to the challenge of providing long-term care in any society, and certainly none that is right for all. Too often, constructs of ethical universals have been developed within a Western framework when it is the lessons and wisdom gained from experiences in both developed and developing countries that shed the greatest light (see “The African Perspective,” page 85). But if resources, cultural norms, and the processes by which decisions are made vary widely, the need to develop solutions that are fair and just can rightly be considered universal. In time, it may be possible to define certain absolutes that must ground long-term care in any society, although the cross-cultural dialogue necessary to that process has not yet occurred. Until it does, countries can at least recognize that the increased demand for long-term care coming over the next several decades means the time to formulate an appropriate response that maximizes choice and opportunity is at hand.

Stated broadly, a long-term care system is comprised of a comprehensive range of services, some based in the home, others based in the community, in health care institutions, and elsewhere. In an optimal and rational model, all of the services and structures that form a system will be designed to allow individuals to lead lives of dignity and, where possible, independence, without placing intolerable burdens on their families. Timely planning offers the best opportunity for Member States to define the fundamental values on which their long-term care systems should be built and then to move forward with the actual design.

The primary goal of this report is to identify some of the issues that need to be considered as part of that process. It reflects a consultation held over a two-day period at the University of Chicago in July, 2002 under the sponsorship of the World Health Organization’s Cross-Cluster Initiative on Long-Term Care. Philosophers, experts in public health and long-term care, and professionals knowledgeable about developing countries came together (see Participant List, page 87) to reflect on the moral basis of long-term care and to point the way forward. Their goal was not to reach consensus but rather to discuss relevant topics from many perspectives and to suggest an agenda for ethical considerations. Much more work in this arena lies ahead.



# 2

## The Societal Perspective

The principles of social cooperation, which call on people to accept an obligation to care for one another adequately, are fundamental to civil society. Examples abound of how society tends to the needs of its members every day—by building roads, maintaining public spaces, and providing education, to name but a few. Society needs an infrastructure, and the benefits from these public goods are shared by all.

Putting respect for human dignity at the center of the social paradigm means accepting laws and social practices that protect the weak and vulnerable from domination, exploitation, or neglect. Everyone comes into the world in a completely dependent condition. Later in life, some individuals will need additional care, while others will not; some will have the financial or family resources sufficient to provide it, while others will not. Yet everyone gains when care that is consistent with respect for the individual is available to all. Society functions best as a harmonious whole, enabling those who have resources to enjoy their full benefits while providing security to those who are less fortunate.

Underpinning the social responsibility for care is the recognition that no activity occurs in isolation; rather, everything affects a larger network. A society that treats its most vulnerable members with compassion is a more just and caring society for all. By promising security to those who become dependent, societies offer insurance during periods of independence, thus placing a claim on the social cooperation of all. With that perspective, societies should not be organized only with the idea of the “normal” person in mind, though they often are. A broader obligation to cater to the needs of those with some sort of limitation must also be recognized. Implied is that all people, including those with disabilities, have the right to function as fully as their condition permits, regardless of their starting place. The challenge then becomes removing any barriers that impede that goal. Moreover, designing services and facilities with the needs of the disabled in mind provides a broader benefit. An environment that is safe for blind or deaf people, for example, will also be safer for children, who often do not use their senses to avoid danger.

Despite a moral imperative and practical advantages, strategies for providing long-term care have been low on government agendas everywhere, and in

## ETHICAL CHOICES IN LONG-TERM CARE

some countries, they have not appeared at all. Little has been done to address challenges already at hand, much less to prepare for the future. The consequences are troubling. If societies abdicate their responsibilities, the burden of care will remain entirely and unfairly on the shoulders of a few—and for some, no care will be available at all.

Experience from industrialized countries amply demonstrates that waiting for unmet needs to reach crisis proportions leads to expensive and ineffective solutions. For example, the failure to plan for long-term care resulted in the construction of institutions for the elderly, the mentally ill, and others that were costly to maintain and poorly suited to the needs of those they housed, their families, or the society. The lessons learned have led in the last decade to the reversal of this approach, with societies now emphasizing families and home-based care and viewing institutions as a necessary “last resort.” Developing countries will be far better served by planning appropriate long-term care systems in advance of urgent needs.

While cultural norms naturally influence systems design, the obligation to understand and respect differing value systems can easily lead to a response that is sensitive only to a society’s dominant voices, excluding the less powerful. This is not inevitable—values can and do evolve. Where prevailing values challenge the implementation of ethical long-term care strategies—for example, because they assume that girls and women will shoulder all caregiving responsibilities—opportunities for dialogue should be sought. Promoting exchanges so that communities operating within different ethical frameworks can explain their reasoning to one another encourages all parties to think more flexibly and to challenge their own assumptions.

**THE REALITIES OF SCARCITY:** Only after acknowledging a fundamental ethical obligation to provide care can a society engage in a discussion of the necessary tradeoffs. Public deliberation can focus on cost thresholds, how best to define “reasonable” accommodation, and where extra costs outweigh the level of benefit—but these are points to be parsed out once the basic obligation is recognized.

Scarcity must certainly be considered in designing long-term care initiatives. In an environment of resource limitations, needs inevitably compete against one another as priorities are established and choices are made. Given the potentially greater vulnerability of the poorest populations, it may be appropriate to consider exposure and outcome by economic strata in resource allocation decisions.

However, available resources should not necessarily be viewed as a fixed bundle. Opportunities exist to expand resources through prudent investments, including investments in human capital. For example, improving access to technologies

that meet the needs of the disabled may allow some individuals to work, especially if employment is flexibly structured. With an enlarged perspective, planners can move past the view of long-term care as an enormous burden and search instead for strategies that liberate talent, match it to opportunity, and in the process create wealth. At the same time, it must be remembered that the fundamental goal of compassionate care is not to generate resources but to care honorably for those in need.

**ISSUES OF GENDER:** Tradition, deeply embedded notions of a woman's social worth and the value of her work, and the distribution of power within a society all explain, in part, why caregiving tasks have fallen disproportionately on women. Two ethical concerns arise: first, women shoulder this burden without being adequately protected and compensated, and second, the implied assumption is that caregiving is demeaning work best left to women.

Optimally, care-giving responsibilities should be shared without reference to gender. Men from developing countries often obtain work as caregivers when they migrate to rich countries, which undermines any stereotypical concept that women alone are naturally disposed to be caregivers. Though it may nonetheless be unrealistic to expect full parity, states can take steps to redefine caregiving as gender-neutral. A place to start is by recognizing that family circumstances or the need to earn a living can push both men and women into family caregiving or other gainful employment.

Promoting care-giving as an opportunity open to all suitable talent fosters equity and shared social responsibility, prepares a larger pool of people to take on the associated obligations in their own families later in life, and improves services. Young boys can be educated to think of caregiving as something they are capable of doing and in which they can take pride. Youth volunteers can be recruited and trained to provide care.

Even if females continue to provide the bulk of the caregiving, certain limitations need to be considered in pursuit of justice. For example, removing a girl from school to care for an ailing relative can sentence her to a lifetime of poverty and unmet potential. In many societies prostitution becomes one of her only economic options, with all of its associated risks. Particularly in light of the HIV/AIDS epidemic, it is appropriate to ask whether this cycle should be broken by a state-enforced prohibition against depriving girls of an education so that they can serve as caregivers.

**BIAS AND DISCRIMINATION:** In an effort to define the entitlements of all members of society, we need to ask when inequalities are unjust and where discrimination needs to be addressed. In addition to a gender bias in the burden of caregiving, age bias may manifest itself in resource allocation decisions, in

## ETHICAL CHOICES IN LONG-TERM CARE

the legal framework, and in the way in which the social obligation to the ailing elderly is defined. There may likewise be a bias towards anyone who is disabled that colors the design of support systems, or that creates unethical distinctions between those whose disabilities can and can not be remedied. There is also in many societies a bias against isolated rural areas, with planning that fails to recognize their special needs and vulnerabilities.

While different moral structures may exist for considering some of these variables, it is important to note that considerations of age, gender, and race—as well as productivity, which is discussed below—are not the best guides for determining access to long-term care. Rather, it is the nature of the disabilities themselves, and the needs of those who are affected by them, that point the way towards the most appropriate strategy for providing care.

**HEALTH REFORMS:** As health sector reforms are implemented, a minimum set of justice-based entitlements needs to be defined and can not be compromised. An opportunity exists to incorporate some elements of long-term care into the package of services that Member States make available to all. Any universal package should be viewed as a starting point, however, not a limitation, so that the subset needs of smaller groups also receive consideration (WHO, 2002b).

Under the guise of health reform, some societies are offloading responsibility from the central government to the least capable and most vulnerable local authorities and family units, without a concomitant decentralization of resources. The expectation that individuals without training, expertise, or support will have to bear burdens that were once more broadly shared should not be endorsed, either tacitly or explicitly, without considerable reflection. Given the burden of long-term care on families, requiring a “family impact statement” on new health initiatives offers a mechanism for assessing the consequences of any action.

**WEIGHING PRODUCTIVITY:** In the face of limited resources, providing preferential treatment to members of society who have the greatest potential to be productive may appear necessary. Yet basic justice requires that respect for persons, not productive capacity, underpin decisions about who gets what. Certainly it has been accepted that productivity is not part of the equation for making decisions about allocating acute care. Where cost-effectiveness analyses are used in acute care, they are tools to assess the effectiveness of an intervention, not the value of restoring someone’s economic capacity. Likewise, the return to the individual, not the return to the society, is the standard against which to measure the value of long-term care.

Only in the most extreme situations can capacity serve as the basis for allocating resources—for example, where the survival of other family members depends on a breadwinner’s access to care. Whatever the societal failures

that force such rationing—and there is a keen need to understand them—it should be clearly understood that justice is not served when economic potential becomes a basis for prioritizing resource use. Any situation where basic moral requirements can not be fulfilled needs to be reviewed and overhauled.

It is also appropriate to note that an individual's contribution to family and community life can not be judged solely on an economic basis. The many societies that venerate the elderly certainly reject this basis explicitly. However, it remains unethical to consider individual worth as a factor when restructuring health systems or allocating resources, even if that concept is broadly defined.

On the other hand, the goal of giving individuals with disabilities a place in society—by providing the resources and opportunities they need to reach optimal capacity—can be legitimately considered in developing long-term care services. Productivity in this framework is neither a criterion for providing services nor a goal; rather, it is a benchmark by which to measure success.

The concept of productivity is also relevant to how we think about work. As globalization becomes an increasingly dominant force, with much of the world moving towards market structures, only economic activities that take place outside the home are typically counted as productive; the task of unpaid, home-based caregiving is usually excluded. With a broader view, productivity would be defined as any activity, paid or unpaid, that contributes to a healthy and functioning society. This is so not merely because unpaid household activity allows the marketplace to function better, although that is surely the case, but also because it invites a richer view of social cooperation and quality of life. The International Labour Office, a United Nations agency, has already taken a step in this direction by redefining caregiving as work, in the same category as wage labour and self-employment, with their mandates of free choice and decent working conditions. This assertion underscores how unethical it is to treat caregiving as akin to forced labour (Daly, 2001).

Finally, it is reasonable to consider productivity from the perspective of what is lost to someone who steps into a caregiving role. Societies may choose to measure the sacrifices of a child who leaves school to become a caregiver differently from those of an adult who gives up paying work. (Lost productivity is not, of course, the only factor relevant here. The lesser decision-making autonomy of the young person also alters the equation, as does the belief in many cultures that adult children have an obligation to their aging parents, whereas young children are themselves in need of care.)

**INSTITUTIONAL CARE:** The decision to place a family member in an institution should not be an act of desperation, as it so often is now, but a reasoned choice. Under the existing paradigm in many societies, families bear the full burden of care until that becomes completely untenable, and then turn

## ETHICAL CHOICES IN LONG-TERM CARE

in despair to institutional options. Where institutional care is perceived as a desperate measure, it tends to be stigmatized and shortchanged on resources and caring staff, heightening the vulnerability of the person needing care.

A starting place for changing both reality and perception is to be explicit that long-term care institutions exist within a community and are not exempt from community ethics and prevailing standards. Any societal commitment of resources to build institutions needs to be accompanied by a commitment to the basic human dignity of those who will use them. This consideration imposes obligations on caregivers and health care professionals, on those who design institutions, on communities and states, and on international agencies and donors.

## 3

## The Role of the Family

Family itself has many definitions. Though we tend to view families as private entities, they are in fact thoroughly social and political institutions, with negotiable rights and privileges. The state decides who counts as family and has the prerogative of altering its definition to embrace other structures.

Given the transitions that have strained caregiving and eroded established notions of the natural family unit, it may be appropriate to take a broader view, based on who is actually involved in caregiving, rather than who is legally considered kin. In an African context, for example, this saying is heard: “The one you are left with is your relation.” In many societies—especially where marriage is less common, where strong ties are not defined solely by blood, and where losses due to HIV/AIDS and other causes have forced traditional bonds to be reconfigured—care is being provided by individuals who would not by most definitions be considered family members. A more encompassing perspective of family conveys respect for the legitimacy and value of these providers, whether or not social benefits are extended to them, and adds to the pool of available resources.

By recognizing that families are neither exclusively, nor necessarily, constructs of biology but are also shaped by social conventions and cultural values, the distinction between what they and society owe an individual needing care begins to blur. Before building systems on the premise that there is a certain, natural role for the family as first-line providers it is useful to question that assumption. In this context, the analogy sometimes made between the parental obligation to children and the family’s obligations to its disabled members is probably more distracting than useful. Whether spouses or adult children of aging parents should dedicate the same level of singleminded devotion as most parents dedicate to their children warrants discussion. The dynamics of these relationships, including the mix of burdens and rewards, are very different. and comparisons that are not fully considered may obscure meaningful analysis.

Recognizing that family involvement is not an immutable law of nature encourages societies to reflect on their own obligations and to consider the defensible expectations that can be placed on families. From there, it is easier to ask:

## ETHICAL CHOICES IN LONG-TERM CARE

- What will families be expected to do, and for whom?
- Which members of the family are expected to shoulder these obligations, and why does the task fall to them?
- What supports can be provided to make the tasks easier?
- What limits should be set on the burdens imposed on family?

Those questions open a door for a conversation about how best to provide social supports that strengthen, rather than undermine, families so that they can fulfill their commitments under reasonable and non-coercive conditions.

**SUPPORTING FAMILIES:** Even when dependent individuals are fortunate enough to have families at hand, we cannot simply assume that the family can provide all needed care. Capacity is a key determinant of the ability to provide care and mechanisms are needed to assess the strength and limitations of family caregivers and to intervene with support and respite as needed. Without such supports, family stability may become threatened, existing systems may be strained to the breaking point, and the larger group may ultimately be imperiled.

While care work can be immensely rewarding, tapping as it does into the love and compassion within a family, stress, anger, and frustration can be equally real. Family members often stagger under the burden and may become sick themselves. Given the absence of good quality alternatives to family caregiving, families may perceive their only choices as total immersion into the responsibilities of long-term care, or abandonment. Too often, that perception is accurate. Yet the belief that complete self-denial is the fullest expression of obligation and love can become a deterrent to commitment. A wider range of options would allow family members to offer care at a lesser personal cost while meeting their own needs and the needs of other family members.

The call for community involvement does not mean creating a bureaucracy to take over the caregiving role once family and friends reach the limits of what they can tolerate. Rather, opportunities for cooperation are needed along the way. Certain elements of caregiving, particularly those that build on personal history, a sense of comfort, and the reassurance of familiarity, lodge most naturally with the family. The resources of the community may be better applied in realms where attentiveness to individual needs is less critical, or where the responsibilities are too physically or emotionally demanding for family members.

Community help is most likely to be of value to families when it is needed and

offered, not imposed. In general, support should be individualized. Often something relatively modest—such as training, access to information, respite care, or opportunities to talk about concerns—is enough to sustain a caregiving relationship. Given the long-lasting and costly nature of long-term care, interventions may also be needed to minimize the risk of impoverishing an entire household.

Whatever the outside involvement, it should enhance, rather than disrupt, the intimate relationships that exist between family caregivers and those to whom they provide care. Families should not be expected to provide complex medical and nursing interventions unless they are confident in their ability to do so; an obligation for oversight and training therefore rests with those who have professional skills. Before certain sensitive responsibilities are assigned to family members—for example, having a child change an incontinent parent's undergarments—the impact of such expectations on the core relationship needs to be considered.

None of this is simple or straightforward, partly because there is a tension between the private realm of the family and the public realm of the state. Much as they need support, families are likely to resist the entry of strangers into the home, even if they come to help. Yet any allocation of public resources to support family caregiving will inevitably be accompanied by oversight. The appropriate balance here should be considered.

For an indepth discussion on the role of and support to families, see chapters 1 & 2 in WHO, 2002c.

***PARTNERSHIPS WITHIN THE HEALTH CARE SYSTEM:*** If the resources of the existing health care and social service systems are to be the first line of support for family-based care providers, communication between the acute care and long-term care systems needs to be improved. One ethical justification for the deeper engagement of the acute-care system may be its emphasis on saving lives, which arguably creates an obligation to ensure that those lives can be properly lived.

To be effective, partnerships between families and health care professionals, including nurses and community workers, need to be based on mutual respect and a recognition of each party's unique strengths. Such partnerships are often challenging to build. Family concepts of intimacy, privacy, confidentiality, and decision-making often clash with the values of health care professionals, who bring their own ways of working into the home and tend to focus on meeting immediate needs efficiently. The involvement of external bureaucracies, each with its own values and culture—including those that set professional standards and determine reimbursement and payment—also complicate caregiving.



## 4

## Other Stakeholders

Discussions of family caregiving assume an individual in need actually has a family. In fact, whether it is defined through blood ties or social constructs, family is for many a weak reed upon which to rely. All societies have “unbefriended” people who are largely alone; in an increasingly mobile world, this population is likely to grow. Childless women are particularly disadvantaged where there is an assumption that one’s offspring will provide care.

Beyond those practical realities lies an ethical perspective that dictates the need for shared responsibility. In a broad sense, it can be said that the world bears some responsibility for each of its states; the state for each of its communities; the community for each of its households; the household for each of its families; the family for each of its members. Responsibility also flows in the opposite direction, with individuals responsible to each of the broader social entities.

The obligations of the state have already been discussed in some detail. Some of the considerations involving the others players are noted below.

**COMMUNITY RESOURCES:** An individual may be a member of many different formal and informal communities and organizations—for example: clans, traditional villages, funeral societies, women’s groups, religious and professional associations, and friendship networks. These caring communities, bulwarks against feelings of isolation and lack of support, often inspire trust and loyalty.

While some communities are already hospitable to the needs of their members for care, others are not engaged. “What is this community care?” asked one family caregiver. “I am the community. I am the care.” Resources, training, and education all help to promote community involvement. For example, telling people whom to call if an Alzheimer’s patient is seen wandering, or educating a populace that the peculiar behavior of a chronic schizophrenic is not dangerous, extends the caring network. In one village, food is placed outside the house of a mentally ill person who fears the entry of others.

At the same time, it is not necessarily fair or appropriate to demand engagement from community organizations that have not defined long-term care as part of their mission. No community can substitute for the state, with its impartiality

## ETHICAL CHOICES IN LONG-TERM CARE

and obligation to treat its citizens equitably; rather, the state must build the framework within which communities can make their contributions.

In practice, the responsibilities of the state and the community are not crisply divided. Civic groups can push for a richer state response to long-term care needs, and fill in service gaps where necessary, but they should not make it easy for government to abdicate responsibility by propagating the myth that “we can take care of our own.” Realistically, however, community involvement allows essential needs to be addressed that might otherwise go unmet, especially where the state is weak or unable to deliver adequate services.

**ROLE OF DEVELOPED COUNTRIES:** The obligation to redistribute resources from richer to poorer countries, already being debated in many other policy contexts, has a special resonance for long-term care. Much of the caregiving in wealthy and developed countries is being provided by care workers, nursing professionals, and others who have migrated from impoverished and developing countries. Recruiters representing institutions from Europe, North America, and the Gulf countries have set up shop at the gates of hospitals and nursing schools even in the poorest countries. While these workers may experience economic benefit, they also create gaps in their own families and communities. Arguably, wealthy nations incur a debt in this exchange that somehow needs to be repaid (for example, by training workers to replace those they have recruited).

Likewise, it is reasonable to ask if the multinational corporations that depend on the natural and human resources in developing countries have a responsibility to fill the gaps in caregiving they help to create. Some corporations recognize an obligation to provide education as part of the compensation due to the communities in which they operate; the case can be made that supporting long-term care is an extension of a similar obligation.

**INDIVIDUAL RESPONSIBILITY:** The issue of personal responsibility—by anticipating, and planning for, a more dependent future; saving money and purchasing insurance policies (where they are available); and engaging in behaviors that foster health—is complex. While this is a legitimate topic for discussion, it needs to be disentangled from many other confounding issues. In particular, emphasizing individual behavior can readily descend into victim-blaming or become an excuse for avoiding social engagement. As well, it is legitimate to ask how much individuals can do for themselves in societies where they are challenged even to remain adequately nourished. Certain government decisions—such as whether to accept investments from tobacco companies or to fund primary care adequately—also shape individual behavior and the overall health of a society, thereby influencing the demand for long-term care.

## 5

## The Caregiving Relationship

Regardless of how a long-term care system is structured, the relationship between the caregiver and the care recipient remains at its foundation. In certain situations their needs and interests are complementary, while in others they are in opposition. Planners may consider individual interests independently, or they may view the caregiving relationship itself as a fundamental unit of analysis; each approach has a degree of legitimacy and some important limitations. Regardless, a benchmark question should always be asked in the course of designing any long-term care system: Does each decision support and strengthen the caregiving relationship?

Individuals who receive long-term care do not have a single condition or a static, predictable set of needs, nor do those who care for them. Long-term care is better conceptualized as a continuum with discrete responses required for particular situations and at particular times. Thus, the needs of adult children caring for chronically ill parents differ from those of parents caring for disabled children. So it is, too, that a caregiver will on various occasions be asked to be an administrator, a nurse, a psychologist, and a disciplinarian.

Understanding the complexities of caregiving relationships also means disentangling the many ways in which the term “caregiver” is defined and the many different relationships to the care recipient that it implies. Individuals who provide hands-on home care may, for example, be unpaid family members or paid workers. In either case, their ongoing involvement distinguishes them from care professionals who are part of the more distant and formal nursing and social service systems, and who have regular, but less frequent, contact with disabled individuals. Administrators and bureaucrats, while not involved in direct care, are also key players whose roles must be understood.

The ethical obligations of caregivers—from the physician in a long-term care institution or clinic, to community workers and family members in the home—have yet to be explored in depth. Professional codes of conduct for physicians, nurses, and others in acute care may provide some useful guidelines but they do not apply in their entirety to long-term care, where the nature of a caregiver’s training and knowledge varies tremendously. More dialogue is needed to develop codes of ethical conduct for caregivers that define

## ETHICAL CHOICES IN LONG-TERM CARE

expectations, competencies, and responsibility, especially in decentralized home settings and over very long periods of time.

**EMPOWERING THOSE AFFECTED:** To proceed with confidence, planners should look to those on the frontlines to bring the realities of their experience to the fore. Where recipients of care and those providing it have a voice in making decisions that affect them, systems are far more likely to meet their needs.

The dialogue between family members and health professionals also needs attention. These players must learn to talk to one another and establish decision-making relationships while ensuring that the individual with diminished capacity, who may be the subject of their conversation, is heard.

Informed consent is another venue in which consultation and listening are essential. The obligation to obtain informed consent looks somewhat different in the long-term care context, compared to acute care, because it must often be extended to the household, clan, or community levels. The special challenges of obtaining informed consent from cognitively impaired individuals and children also need to be addressed.

**MINIMIZING THE POTENTIAL FOR ABUSE:** Too often the person to whom care is being provided is viewed as incompetent, indeed “lesser” in every way, and therefore a ready target for exploitation or neglect. The stress of unsupported caregiving may increase the likelihood that a care recipient will be abused in some way. Sadly, the abuse of power can go in the opposite direction as well, subjecting the caregiver to the “tyranny of the ill.”

While more research will shed light on the systematic ways in which some dependent people suffer, it is surely possible now to identify behaviors that are prohibited under all circumstances. Though certain cross-cultural differences may exist in defining abuse, there is no ethical justification for exploiting an individual’s vulnerability (WHO, 2002d).

**THE PRIORITY OF COMPETENCY:** Anyone who needs long-term care should feel confident that those who provide it, whether paid workers or family members, have the required knowledge, training, and skills. Two sets of competencies are required: caregivers must be able to deal competently with the complex medical issues that arise, and they must have the appropriate interpersonal and human relations skills. In noting that there is an obligation for professional caregivers to be competent, it is tempting to suggest that the principles established for acute-care providers offer a model. However, that assumption can not be made uncritically, given that in some places licensing requirements and regulations to ensure competency in the domain of acute care are essentially non-existent or do not extend to all providers. Nor are the skills appropriate to acute care necessarily sufficient for long-term care.

**ON RESPECT AND COMPENSATION:** Where caregiving is paid work, it is likely to draw more talent if it is located along a career path, rather than at a dead end. Equitable compensation, attractive working conditions, and access to training and advancement within the health care system all enhance the rewards of caregiving, as do structures that foster continuity and personal connections between the caregiver and recipient.

**APPROPRIATE OVERSIGHT:** Though many people who work with dependent individuals are remarkable in their dedication and skill, the larger society is responsible for ensuring the quality of the care offered to those who are most vulnerable. As they commit resources, states will also need to exercise responsible leadership and impose appropriate oversight to ensure that their systems are held to the ethical standards they have defined.



## 6

## Long-Term Care and Social Justice

WHO's effort to stimulate a much-needed consideration of ethical principles in long-term care necessarily proceeds at several levels of generality and abstraction. Deliberations can move simultaneously from concrete experience to theoretical principles, and back again.

WHO proposes that discussions begin with the description of the challenges of providing care to meet projected needs, and an assessment of the cultural values that underlie existing systems. Questions to illuminate current practices include these: Who gets care, and how much? Whose job is it to provide care? These in turn encourage a look at whether existing approaches are sufficient, given future needs, and whether benefits, responsibilities, and burdens will be allocated fairly. Also important is an understanding of who will be asked to sacrifice what, and for the sake of whom, drawing on insights from diverse cultures at differing levels of economic and social development.

National traditions, as expressed through religious, political, and cultural articulations of value, are a starting point for this assessment. Because the challenges looming just ahead for most countries are novel and difficult, however, these traditions will need to be adapted to new circumstances. A process of self-examination and growth, enriched by dialogue both within and across national boundaries, may open questions previously regarded as settled.

At the highest level of generality, WHO also seeks to introduce the ethical issues that arise in long-term care into ongoing efforts to fashion a coherent and appealing general theory of justice. Thus, exploring the ethical underpinnings of long-term care can guide societies as they decide how to allocate the benefits and burdens of social cooperation. The most fully articulated theories of justice have been products of philosophers and political theorists, and their enterprise is in vigorous and healthy development today. WHO's effort to interest these theorists in long-term care provides an important focus for some of the ethical debates currently underway; until now, this has been largely neglected. If the stimulus to theories of justice can help bridge the distance between abstraction and the real-world dilemmas of long-term care, it may in time yield insights of use to the long-term care policies of Member States. It is also possible that the challenge of addressing long-term care policy will sharpen and improve the theories themselves.

## ETHICAL CHOICES IN LONG-TERM CARE

To initiate this theoretical development, WHO has commissioned a philosophical paper by Professor Martha Nussbaum, of the University of Chicago's faculties of law and philosophy. Professor Nussbaum, one of the most widely-read contemporary philosophers of justice, takes as her starting point the great tradition of the theory of the social contract, which can be traced back not only to Western philosophers of the 17<sup>th</sup> century and later, but also, in different forms, to numerous philosophical, cultural, and religious traditions around the world. In essence, theories of the social contract are based on the premise that social cooperation, including reciprocity between citizens and acceptance by the people of at least some of the powers of the state, is justified by the potential advantages and protections that social cooperation in a just society can offer the individual. Social contract theories attempt to spell out the terms of the just society thus conceived, including the roles, rights, and responsibilities of individuals and the state. Contemporary theories, in particular, also try to define the basic principles for allocating material and social benefits and privileges, as well as burdens, for citizens acting in the range of available social roles.

Social contract theories have been extremely influential, not only among philosophers, but also in the law, in the social sciences, and in the design of states and their constitutions. Prominent among contemporary theorists has been Harvard philosopher John Rawls, whose *Theory of Justice* (Rawls, 1971) is widely accorded the highest stature among 20th-century works of social and political philosophy.

Professor Nussbaum's inquiry on the values underlying long-term care asks a series of searching questions about the adequacy of the social contract, and in particular Rawls's articulation of it, in addressing the needs of those who are dependent. In her view, the notion of the social contract starts with the picture of people bargaining among competing visions of how society should be constituted. In reality, many of those whose needs will be most pressing, and who will have to count on the workings of the institutions of justice, will not be a party to this kind of bargaining, since they may lack the required capacities. Who, then, speaks for them? And how can their distinctive need—the need for care—be established as a primary good that the state will secure if necessary?

While Professor Nussbaum finds much to admire in the social contract tradition, and in particular in Rawls's theory, she argues that understanding society's ground rules as the result of deliberation among people conceived as bargainers—i.e., as rational strategists, not flesh-and-blood creatures—should arouse caution. Real human beings are a species with the capacity not only to think and bargain, but also to become frail, ill, and disabled; they cannot survive without the care of others. If social contract theories, in their idealization of society as a group of rational individuals bent on cooperating for mutual advantage, overlook these vulnerabilities, then Professor Nussbaum asks

whether we might look for alternatives; or, at the least, find a way to adapt the social contract to recognize our frailties and the likelihood of dependency at some point in our lives. Moreover, in her view, care should be at the forefront of the essential and all-purpose good that the social contract allocates to its participants. The result, she says, would be a step forward in theories of justice, and the eventual effect would be felt by human societies around the world, which derive part of their sense of what is just from these theories.

Two commentaries by other philosophers who participated in the July, 2002 consultation are also included here. Professor Norman Daniels of Harvard University, author of *Am I My Parents' Keeper?* (Daniels, 1988) and other works on justice, takes issue with Professor Nussbaum's argument that the social contract tradition, and Rawls's theory in particular, ignores the need for care and fails to give it the priority it deserves among social goods. In his understanding, idealizing the parties to the social contract as autonomous, rational individuals does not suggest they are anything other than flesh-and-blood creatures prone to illness, aging, and dependency. Rather, Professor Daniels argues that theories of the social contract, including Rawls's, leave room for an emphasis on care, even if this is not among the primary social goods whose distribution is initially addressed in the theory.

Professor Eva Kittay, of the State University of New York at Stony Brook, author of *Love's Labor: Essays on Women, Equality, and Dependency* (Kittay, 1998), among other philosophical works, comments on both views. Kittay focuses on two key issues: the burden of caregiving and its effect on the caregiver's opportunities; and the status of people who have not, and never will, contribute to society's stock of resources because of the extent and the nature of their impairments. Though the latter group is small, Kittay notes that what we say about them will apply to all of us in varying degrees, especially given that we are all vulnerable to being so incapacitated. While she is sympathetic to Daniels's defense of contractualism understood as addressing the capabilities which society should try to provide, or restore, to each citizen to keep their opportunities open, she is concerned that this conception excludes those who may never be able to contribute to a society's material resources. Like Nussbaum, she is interested in orienting our view of society to its role in the care and sustenance of those who are dependent and argues that a contract model is less amenable to the concept of a social responsibility for care.

The disagreements among these philosophers may seem to be fine points, given that they agree on much more than what divides them; moreover, they support the same broad conclusions. However, these theories have a vast reach and when applied and extended they address some of the broadest issues of fairness in allocating social resources of all kinds. Thus, minor differences among theories of justice may result in significant differences in

## ETHICAL CHOICES IN LONG-TERM CARE

the burdens and benefits assigned to some parties. The philosophical argument now underway is not yet about the conclusions to be reached, but about the premises to be adopted. Given their potential significance, it is important that we examine these with an eye toward long-term care and the needs of the aged, the sick, and the dependent. WHO supports this effort among philosophers and also seeks to encourage adaptations and applications to diverse national systems of long-term care.

# 7

## The Way Forward

This report represents only a first step in the process of building an ethical framework for designing and implementing long-term care systems. Though the deliberations that lie ahead are nuanced and complex, at least this can surely be said now: some level of responsibility for long-term care rests at every level of social organization. How best to assign those responsibilities will remain the subject of scrutiny and dialogue for some time to come.



## 8

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# appendices



## appendix

# A

### Long-Term Care and Social Justice: A Challenge to Conventional Ideas of the Social Contract

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Martha C. Nussbaum

*It will be seen how in place of the wealth and poverty of political economy come the rich human being and rich human need. The rich human being is...the human being in need of a totality of human life-activities.*

Marx, *Economic and Philosophical Manuscripts of 1844*

#### A.1 AN ACUTE PROBLEM OF JUSTICE

All societies contain people in need of care. Indeed, all people in all societies are in need of care. Even so-called “normal” and “able-bodied” adults rely constantly on care provided by others in the fabric of their lives: people who cook meals and tend the home, providers of regular health care, people who prepare the external environment so that it is safe and conducive to ordinary functioning. At times during their lives the “normal” have more acute needs for care: during an illness, after an accident, etc. But of course “normal” adulthood is itself a temporary phase of a human life. It is preceded by a very long period of childhood, much longer than in most animal species, during which basic needs for food, comfort, shelter, cognitive development, and social interaction must be met by the constant involvement of adult givers of care. This period can last for over twenty years in many cases, though of course the nature of the needs in question shifts over time.

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<sup>1</sup> This essay is a short version of a much longer argument in my book in progress, *Beyond the Social Contract: Toward Global Justice*, The Tanner Lectures in Human Values 2002, forthcoming from Harvard University Press. Those who would like to see how I engage with Rawls in more detail, and how I answer the points made by Daniels, can consult those lectures on the Tanner website of the Australian National University, Canberra. My own version of the Capabilities Approach, as an approach to a minimal theory of social justice, is given in *Women and Human Development: The Capabilities Approach*, Cambridge and New York, Cambridge University Press, 2000, and in “Capabilities as Fundamental Entitlements,” *Feminist Economics*, forthcoming 2003.

## ETHICAL CHOICES IN LONG-TERM CARE

The phase of “self-sufficient” adulthood is usually followed, in turn, by a period of increasing dependency, as aging gives rise to new physical and mental needs. The increasing life expectancy in many nations of the world is giving rise to a new, or newly numerous, set of dependencies, as children who have just raised their own children, or are still doing so, must care for their own parents in their physical and/or mental decline.

There are many citizens in every society, moreover, who are asymmetrically dependent upon others throughout their lives. In some cases these dependencies result from unusual physical disabilities. All human beings are disabled beings, with many imperfections in judgment, understanding, perception, and bodily functioning. But society is typically arranged to cater for the most typical disabilities, so they do not become handicaps.<sup>2</sup> Thus we do not find staircases so high that only the giants of Brobdingnag can climb them, nor do our symphony orchestras play at frequencies inaudible to the human ear and audible only to dog ears. When a person is blind, or deaf, or has to go around in a wheelchair, societies are not so well adjusted to make such persons fully mobile, fully able to occupy public space on a basis of equality. What blind law professor Jacobus Ten Broek called “the right to be in the world” is unevenly extended to its citizens, and people who could perfectly well get around if the streets were maintained in a particular way, for example, are put by social contingency in a position of dependency— on a dog, other humans, a network of support.<sup>3</sup>

Other citizens have disabilities that make dependency on others a virtually inevitable fact of their daily lives. People with severe mental disabilities, for example, may never be able to live on their own, and some rely on caregivers for their most basic bodily needs.

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<sup>2</sup> In the literature on disability, the terms “impairment” and “disability” are typically used of a limitation in function that is, so to speak, internal to the person; the term “handicap” is used to refer to the burdens and difficulties the person faces in the world, many of which are social in origin.

<sup>3</sup> See Broek T. “The Right to Be in the World: The Disabled in the Law of Torts,” *California Law Review*, 1996, 54:841-919. He points out that the tort law of his time allowed a blind person like himself to bring a damage suit for negligence against, say, a municipality that maintained its streets in an unsafe way, only if that person was escorted by either a sighted person or a guide dog. He proposes, instead, that the streets ought to be maintained in a way that would make them safe for sighted people at night and blind people during the day, and that departure from this norm defines a standard of negligence. He movingly indicts the legal situation of his day as one that is demeaning to the blind person’s desire for independence and full participation in public space:

“No courts have held or even darkly hinted that a blind man may rise in the morning, help get the children off to school, bid his wife goodbye, and proceed along the streets and bus lines to his daily work, without dog, cane, or guide, if such is his habit or preference, now and then brushing a tree or kicking a curb, but, notwithstanding, proceeding with firm step and sure air, knowing that he is part of the public for whom the streets are built and maintained in reasonable safety, by the help of his taxes, and that he shares with others this part of the world in which he, too, has a right to live.”

Who does all the work that care requires? In a vast majority of the cases, women.<sup>4</sup> Indeed, the most ubiquitous and long-lasting conception of the woman, in virtually all countries and traditions of the world, is as a giver of care: homemaker, mother, wife, tender of the needs of the elderly—in general a supporter of the needs and ends of others. Often this conception of the woman sees her as a *mere* means to the ends of others, rather than as a source of entitlements in her own right, a being who ought to be treated as an end in herself. Thus, women’s caregiving function has often been understood to remove them from candidacy for full citizenship and for many aspects of employment, especially wage-earning work outside the home.<sup>5</sup> Even when women are legally entitled to work and participate in citizenship, their heavy responsibilities in the home often make it difficult for them to do so.

Nancy Folbré uses a vivid image for this situation:<sup>6</sup> it is as if society, in trying to get ahead, allows some people to run in the race without any handicap. Others have to run carrying other people (children, the sick, the elderly). Obviously enough, those in the second group will lag behind from the point of view of their personal goals and their contribution to society outside the home, even though the work they are doing is obviously essential to the survival and well-being of society. This will be true of all who bear a disproportionate burden of housework and care in addition to other work they do. Even in societies where women

<sup>4</sup> To take just one example: According to the U.S. Department of Labor, Women’s Bureau (May 1998), an estimated 22.4 million households—nearly one in four—are providing home care for family members or friends over the age of fifty. For these and other data I am grateful to Harrington M. *Care and Equality*, New York, Knopf, 1999. This is a major theme in recent feminist work: see especially Kittay EF. *Love’s Labor: Essays on Women, Equality and Dependency*, New York, Routledge, 1998; Folbré N. “Care and the Global Economy,” background paper prepared for the *Human Development Report 1999*, United Nations Development Programme, New York, Oxford University Press, 1999, and, based largely on Folbré, chapter 3 of *Human Development Report 1999*; see now Folbré N. *The Invisible Heart: Economics and Family Values*, New York, The New Press, 2001; Williams J. *Unbending Gender: Why Family and Work Conflict and What to Do About It*, New York, Oxford University Press, 2000; Harrington M. *Care and Equality*. Earlier influential work in this area includes: Fineman MA. *The Illusion of Equality*, Chicago, University of Chicago Press, 1991, and *The Neutered Mother, the Sexual Family and Other Twentieth Century Tragedies*, New York, Routledge, 1995; Ruddick S. *Maternal Thinking*, New York, Beacon Press, 1989; Tronto J. *Moral Boundaries: A Political Argument for an Ethic of Care*, New York, Routledge, 1993; Held V. *Feminist Morality: Transforming Culture, Society, and Politics*, Chicago, University of Chicago Press, 1993; West R. *Caring for Justice*, New York, New York University Press, 1997. For an excellent collection of articles from diverse feminist perspectives, see Held V, ed. *Justice and Care: Essential Readings in Feminist Ethics*, Boulder, CO, Westview Press, 1995.

<sup>5</sup> For just one typical example, see *Bradwell v. Illinois*, 83 U.S. (16 Wall.) 130 (1873), in which the U.S. Supreme Court, upholding an Illinois law that made it illegal for a woman to practice law, declared that woman’s role in the family “evidently unfits” her for “many of the occupations of civil life.”

<sup>6</sup> See “Care and the Global Economy,” cited above.

## ETHICAL CHOICES IN LONG-TERM CARE

are heavily involved in family agriculture (for example, much of sub-Saharan Africa), women typically face extra burdens, insofar as they are expected to do most of the housework and child care in addition to their other work. (Women in Sub-Saharan Africa, however, typically do somewhat better than poor women in economies that do not encourage women to work outside the home, because at least the non-care work that they do is perceived as work and enhances their bargaining position in the family.<sup>7</sup>)

The problem of care is a complicated logistical problem for any society. It is also, most emphatically, an ethical problem, a problem that must be addressed not only with resourceful policy thinking but also with the best normative thinking that we can muster. All too often, economic thought addressing this problem proceeds as if it is only a matter of efficiency, and not, as well, a matter of justice and equity. The first step in addressing this problem well is to recognize that it is an ethical problem, a problem of justice. We will only work out good strategies to solve it if we first map out clearly the goals toward which we want policy to work, and offer sound normative reasoning supporting our choice of goals. Here as elsewhere in the international development world, the simple language of economic efficiency must give way to a more complex, more reflective language of full *human development*, and to a debate in which we reflectively identify some especially central goals for a process of human development. As the late Mahbub Ul Haq wrote in the first of the *Human Development Reports* of the United Nations Development Programme, “The real wealth of a nation is its people. And the purpose of development is to create an enabling environment for people to enjoy long, healthy, and creative lives. This simple but powerful truth is too often forgotten in the pursuit of material and financial wealth.”

### A.2 SOME MINIMAL GOALS

What shall those more complex goals be? In this paper there is of course no space to offer a full account of this difficult matter, and it would be inappropriate in any case to attempt such an account, given that the appropriate goal for this project would be to propose a set of normative guidelines that will command wide agreement among people who otherwise differ about what goals societies should be promoting. In the context of such an enterprise, it would be inappropriate to rest the argument on a particular kind of controversial theory of development, however attractive. So, following the procedure of the *Human Development Reports*, let me simply mention some matters that seem uncontroversially

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<sup>7</sup> See Sen A and Drèze J. *Hunger and Public Action*, Oxford, Clarendon Press, 1989, arguing that women in Africa thus command a more adequate share of food and basic necessities. For the fundamental analysis of different work patterns in agriculture, see Boserup E. *Women's Role in Economic Development*, New York, St. Martin's Press, 1970.

central in thinking about a society's quality of life, in areas that are pertinent to care. First of all, as the Reports repeatedly insist with their constant focus on inequalities in basic life chances, a just society would minimally be one that offered to all its citizens, regardless of birth or race or sex or disability, *decent life chances* in areas including, though hardly limited to, *health, education, employment, and political participation*. Both the caregivers and those for whom they care, then, should have decent life chances in these areas. And (as the *Human Development Reports* imply by their constant focus on the measurement of inequalities), they should be given these opportunities on a basis of *equality* with other citizens: no group should be turned into second-class citizens by accidents of birth or race or sex or disability. Implicit within these twin emphases on equality and basic life chances is another goal, more elusive but extremely important: that of giving all citizens the *social bases of self-respect*. John Rawls called this the most important of the "primary goods," goods that all people can be assumed to want whatever else they want, as crucial to the formation and execution of any life plan.<sup>8</sup> Both the cared-for and the caregivers, then, should have their self-respect protected, so far as it is within the power of social institutions to do so.

These are highly general goals: but they have teeth, particularly when we consider the area of care. On the side of the cared-for, most societies are very far from providing the long-term disabled with opportunities for adequate health care, education, employment, and political participation. As Ten Broek so trenchantly put it, social institutions frequently deny the disabled "the right to be in the world," to occupy public space on a basis of equality with others.<sup>9</sup> The mentally disabled, especially, lack support for their educational development and for the political participation of which they are often quite capable.<sup>10</sup> When we add to the issue of decent life chances that of *equality*, these problems become larger. The denial of suitable education to mentally disabled children, including the "mainstreaming" of the disabled in classrooms for "normal" children where feasible and appropriate, has been found by U.S. courts to be a violation of the equal protection clause of the U.S. Constitution, much in the way that schools segregated by race were found to be an equal protection violation.<sup>11</sup> On the

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<sup>8</sup> Rawls J. *A Theory of Justice*, Cambridge, MA, Harvard University Press, 1971. Rawls's concept of primary goods will be discussed further below.

<sup>9</sup> For more discussion, see the essays in Francis LP and Silvers A, eds. *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*, New York and London, Routledge, 2000; and Silvers A, Wasserman D, and Mahowald, M. *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*. Lanham, MD, Rowman and Littlefield, 1998.

<sup>10</sup> See Levitz M and Kingsley J. *Count Us In: Growing Up With Down Syndrome*, New York, Harcourt Brace, 1994; and Bérubé M. *Life As We Know It: A Father, A Family, and An Exceptional Child*, New York, Pantheon, 1996.

## ETHICAL CHOICES IN LONG-TERM CARE

side of the caregiver, once again there are decent life-chances issues. Women who must shoulder the burden of care for a dependent are frequently greatly hindered in education, employment, and political participation, and their health frequently suffers as well. These issues, once again, become larger when we raise the question of equality: if women face an undue burden, it is all the more inappropriate for being one that is given to them unequally, in a way that unequally limits their life chances.

Finally, the issue of *self-respect* is obviously of crucial importance, both on the side of the cared-for and on that of the caregiver. Care for elderly and disabled people is frequently offered in ways that subvert dignity and self-respect. At one extreme here are citizens like Ten Broek, who plausibly insist that it is a terrible insult to their equal competence to be made to accept limitations on their use of public space on account of their disability; what they seek is recognition for their equal capacity to participate fully in society. At the other extreme are elderly and disabled persons who are not capable of autonomy or full social participation; for these people, too, respect for human dignity needs to be a central goal of the caregiving process. It is important to recognize that the Ten Broek group is larger than we think: disabilities such as Down Syndrome, treated appropriately in the early years, can yield a life of very full inclusion and participation.<sup>12</sup> Elderly people, too, are far more capable of many types of functioning, given appropriate support, than they have typically been thought to be. Many problems that have been regarded as inevitable consequences of aging are actually due to treatable diseases, such as depression. Protection of the self-respect of the disabled thus requires complex thought about many different types of disability.

On the side of the caregiver, self-respect again poses urgent problems: work in the home is typically not respected as work and is not considered to be work in the way nations typically keep economic accounts. The category of the “productive” worker has usually been distinguished from that of workers in the

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<sup>11</sup> *Pennsylvania Association for Retarded Children v. Pennsylvania*, 343 F. Supp. 279 (1972); *Mills v. Board of Education* (District of Columbia, 1972). I discuss these cases and the issues they raise at length in *Hiding From Humanity: Disgust, Shame, and the Law*, Princeton, forthcoming from Princeton University Press in 2003. The allocations of funds under the Individuals with Disabilities Education Act (IDEA), which responded to these cases, have been much criticized on the grounds that the definition of “learning disability” is vague and open-ended, and encourages states to classify normal-slow children as disabled, in order to get access to federal funds: see Kelman M and Lester G. *Jumping the Queue: An Inquiry into the Legal Treatment of Students with Learning Disabilities*, Cambridge, MA and London, Harvard University Press, 1997. But even Kelman and Lester grant that the law works well for children who have severe disabilities that have a precise medical definition, such as Down Syndrome, autism, etc., and that, given the emphasis on “mainstreaming,” the law does not impose impossible financial burdens.

<sup>12</sup> See Levitz and Kingsley; see Bérubé.

home, as if work in the home is not productive and does not contribute to society's productivity.<sup>13</sup> More informally, women who care for children, disabled people, and elderly people in their own home are usually treated as if they have no occupation. Even when this work is paid work, it is given low respect. Thus, in a 1975 U.S. government survey in which people were asked to rank types of employment by the amount of skill involved, the jobs of (paid) foster parent and nursery school teacher ranked right at the bottom, next to people who shovel wastes and the job called "mud mixer helper."<sup>14</sup> Moreover, the self-respect of caregivers is often seriously undermined by the sheer difficulty of pursuing life-plans of one's own while doing the work required to care for others. Especially in modern societies in which people's sense of worth is frequently tied to a career and success in it,<sup>15</sup> people who stay at home, or who work part-time because of burdens of care at home, are at high risk for depression and a sense of low worth.

Addressing the problems of care has at least three distinct aspects, on the side of the caregiver: the *allocation of caregiving responsibilities within the household*, the support (or lack of support) for caregiving on the part of the *public sector*, and the *structure of jobs and careers*. Women are disabled by caregiving responsibilities, to the extent that they are, in part because men do not do anywhere near half of the housework, child care, disability/illness care, and elder care, even in two-career or two-job households. Raising women's awareness of their worth and their (at least nominal) opportunities is surely one task of human development. But to have any hope of changing real life this task needs to be accompanied by the task of educating men to see worth and manliness in ways that are not incompatible with doing more care than men typically do. The recognition of this issue is not restricted to "developed" countries but is a prominent part of the development process. To cite just one example, Adithi, a prominent NGO in Bihar, India, which focuses on the empowerment of women through labor organization and education, also runs a training program for male teachers who teach boys in the public schools. Here these male teachers reflect about how they can get young boys to see that housework and child care are not shameful. When I visited the

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<sup>13</sup> A formative example of this way of speaking is in Adam Smith's *The Wealth of Nations*.

<sup>14</sup> From Ruddick S. *Maternal Thinking*, Boston, Beacon Press, 1989, quoting Howe LK, *Pink Collar Workers*, New York, Avon, 1977, p. 237.

<sup>15</sup> I mean here not "developed" as contrasted with "developing" countries, but all societies influenced by the idea that work is integral to one's self-definition and worth. Ancient Western societies were very different: ancient Greece, for example, understood work to be a baneful necessity, and a diminution of one's worth. The modern Western version of this idea probably has Protestant origins; but, whatever its origins (and they are probably multiple, in different traditions), it is by now very widespread.

## ETHICAL CHOICES IN LONG-TERM CARE

Adithi project in the Sitamarhi district in northern Bihar, they boasted proudly of their success: “In every household in this district,” I was told, “you will see boys sweeping, caring for the body, even cooking.” Although it is hard to know how exaggerated such rosy claims may be, the very awareness of the issue is itself progress.

*Public sectors* in different countries vary greatly in the extent to which they subsidize parental leave, public child care, elder care, and care for people with disabilities. Women who care for a dependent or dependents without having any choice in the matter will have new freedom to *choose* to care for a loved one if the state makes alternative modes of care (in-home nursing, for example) available as part of a basic health care scheme. Such policies may also remunerate the caregiving work of family members. Eva Kittay, among others, has recommended a cash payment to the household for purposes of care, which can be used either by the members of that household for their own purposes, or to hire outside help. In this way, she argues, care will be clearly recognized as paid work, and given dignity, even when, as will often happen, a member or members of the household prefer to care for an elderly or disabled or young relative themselves.<sup>16</sup> State policies decisively influence the fortunes of physically and mentally disabled people in other ways, influencing what types of specialized health care and education they are entitled to claim. State policies also influence the issue of allocation within the home; for example, parental leave that can be shared between men and women strongly encourages males to do more caregiving. One obvious need is for a centralized pooling of experiences with these different types of policies, and a study of the extent to which state action actually makes a difference in the choices women are able to make.

But state action is limited in its effects by the policies of private employers. In all countries of the world, jobs and careers differ greatly as to whether they provide the flexibility that many caregiving adults, male and female, need if they are to fulfill both work responsibilities and caregiving responsibilities. The lives of poor women in India are typically shaped, generation after generation, by employer inflexibility. For example, poor sharecroppers in Bihar, whose employers insist on a long day without breaks for housework or child care, often have no choice but to turn over household tasks (including care for family-owned animals) to their female children, keeping them out of school for this purpose. If the household contains an elderly or disabled relative, girls are even more likely to be kept home. Such decisions do not necessarily reflect sexist thinking; they may only reflect economic reality, since educated boys have greater job opportunities than educated girls. Thus inequality perpetuates itself from generation to generation. In “developed countries” with successful schemes of compulsory education for children, the likely outcome of this type

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<sup>16</sup> Kittay EF. *Love's Labor*.

of tension is for the adult woman to “elect” part-time work or work on a “track” that does not promise much job advancement. Unfortunately, most careers still define the successful worker as the full-time worker and define part-time workers, or workers who take extensive leave, as second-class workers. A macho ethos still prevails in the workplace, according to which the good worker is the one who puts in long hours and takes little time off. Such policies (especially common in the U. S., with its tradition of valuing overwork and devaluing leisure) discourage ambitious men from doing care in the home or taking parental leave, even when it is available. Young lawyers in the U.S., for example, have no chance of advancement to partner if they choose the flexible part-time “mommy track.” Although some firms provide on-site child care, there are few who do not subtly frown on workers, male or female, who seem to need it.

The workplace problem has, of course, another face: that of the recipient of care. Workers who are disabled in various ways need accommodation if they are to be able to work productively. Employers often fail to provide such accommodation. In almost all nations, blind and deaf employees, people with a wide range of physical disabilities, and even the mentally disabled can do valuable work if the environment supports them; to the extent that they can do such work, they are more independent and less likely to need full-time care. But such accommodations are often costly, and employers are reluctant to hire such employees. Some nations have made virtually no progress in integrating people with disabilities into the labor force; stigma remains prohibitive. In the many nations that have made serious efforts to alter the workplace to suit the needs of disabled workers, litigation continues over what a disability is, what obligations it imposes, and what a reasonable accommodation would be.<sup>17</sup>

So: care must be supplied to those who need it, without exploiting the givers of care. All must have decent life opportunities and self-respect, on a basis of equality with others. At present, in all nations of the world, this difficult social problem has not been solved.

These problems need to be approached from many angles. We need better data about their extent, and more comprehensive accounts of how different nations and local governments are addressing them. We need more comprehensive studies of different career structures, in order to be able to imagine models that promise good solutions for caregiving adults.<sup>18</sup> But we also need to ask whether there are deeply entrenched ways of thinking in many societies that militate against the full and fair solution of these problems. The present paper will pose that question, and offer an affirmative answer.

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<sup>17</sup> See Francis and Silvers, cited above.

<sup>18</sup> See Williams, cited above.

## ETHICAL CHOICES IN LONG-TERM CARE

This paper, then, will be a conceptual and theoretical essay, intended to complement the more empirical treatments of the problem of care. The paper criticizes dominant models of society as a social contract and recommends a new theoretical perspective based on the idea of “human development” and that of fostering human capabilities. I shall argue that the general way of thinking about society, its citizens, and its goals fostered by the social contract tradition and by now widely disseminated around the world is one large part of our problem. It has created a blinkered way of thinking about need, dependency, and dignity that make it hard to place care in a sufficiently prominent place on the agenda of society, and to give it the support it deserves. By contrast, I shall argue that a perspective based on ideas of human capability and functioning can more adequately deal with issues of social justice raised by the need to provide care for the elderly, the lifelong disabled, and others in a state of extreme and asymmetrical dependency.

Abstract images of human interactions may seem very far away from the daily stuff of political problem-solving. And yet we all think of ourselves in ways influenced by abstract pictures of what a human being is, and these ways shift over time. The importance of such abstract concepts is well known in the history of feminist thinking about law and social justice. Concepts such as those of rape within marriage and sexual harassment in the workplace are not self-evident. For many centuries it was supposed that marriage on its own gave a man a title to intercourse whenever he wanted, without waiting for the wife’s consent. And in the workplace it was assumed that to ask for sexual favors was perfectly unproblematic. Feminist theory, building on people’s experience of indignity and inequality, created these theoretical concepts and helped prepare the way for legal and political change. Theory needs to be securely anchored in experience if it is to be adequate, but the dominant theories are often theories that respond to the dominant voices. We need critical theories, which listen to the experiences of the oppressed and take their orientation from these facts of inequality. The type of conceptual criticism carried out by the feminist movement and its methods of “consciousness raising” have turned out to be profoundly practical.

This is just one example of the way in which pervasive images of the person shape social and political thought; the reflective critique of such images can reshape thought. I shall argue that the social contract tradition has shaped widespread ways of thinking about care, in ways that have deformed our conceptualization of the problem and its solution. I shall offer a critique of the image of the citizen proposed in that tradition and argue for a way of reshaping it that retains many of its best insights concerning the importance of dignity, agency, and reciprocity, but lacks its most troubling defects.

### A.3 THE SOCIAL CONTRACT PERSPECTIVE

Western philosophy's dominant approach to formulating an account of basic social justice has been to imagine society's institutions as resulting from a "social contract," in which parties come together to achieve the benefits of cooperation.<sup>19</sup> Typically the parties are imagined as roughly equal in ability, and the partnership is imagined as one that is profitable to them all: by cooperating they each get more than they could get by not cooperating. This very structure itself requires a situation of rough parity among the parties, for the arrangement will only prove profitable to all if no one is so placed as to dominate the others, as David Hume and John Rawls point out. For this reason, theorists in the social contract tradition omit situations of asymmetrical or lifelong dependency from their accounts of how society's basic institutions are designed. In this section I examine the problems this creates for John Rawls's account of justice, and the challenge posed to that theory by Eva Kittay and other feminist philosophers. I argue that the difficulties are deep and cannot be remedied by a mere modification of the contractarian perspective.

The general idea of the social contract tradition is that we can generate a morally satisfactory account of the principles underlying political cooperation if we imagine a hypothetical situation in which people come together to choose the principles in accordance with which they will henceforth live. This situation does not represent any real historical situation; instead, it is a model embodying some of our deepest moral convictions, and it is supposed to help us think about the moral core of basic political principles. Similarly, the contractarian thought experiment is not claiming that the people it represents are realistic models of actual people; they may be simplified in many ways, and in some cases the relevant attributes of persons may be represented in the model as features of the model situation, rather than of the psychology of the hypothetical people.

It is important to keep these facts in mind. John Rawls's contracting parties in the famous "Original Position" have frequently been criticized by feminists for lacking compassion and altruism, and the inference has been made that Rawls thinks these attributes of persons unimportant. This is a misreading of Rawls.<sup>20</sup> The imaginary people represent just one part of what Rawls thinks moral ratio-

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<sup>19</sup> Some of the material in this section is drawn from my April 2000 Presidential Address to the Central Division of the American Philosophical Association, "The Future of Feminist Liberalism," *Proceedings and Addresses of The American Philosophical Association*, November 2000, vol. 74:2, pp. 47-79.

<sup>20</sup> See my "Rawls and Feminism," forthcoming in: Freeman S, ed. *The Cambridge Companion to Rawls*, Cambridge, Cambridge University Press, 2002. In the subsequent discussion I refer to the following works of Rawls J.: *A Theory of Justice*, Cambridge, MA, Harvard University Press, 1971; *Political Liberalism*, expanded paperback edition, New York, Columbia University Press, 1996; the Dewey Lectures, "Kantian Constructivism in Moral Theory," *The Journal of Philosophy*, 1980, 77:515-71.

## ETHICAL CHOICES IN LONG-TERM CARE

nality involves: the aspect of prudential rationality. Altruism and moral impartiality are represented by the veil of ignorance, which denies them knowledge of their particular place in the resulting society. Rawls repeatedly states that the combination of prudential rationality with ignorance is meant to capture the real-life moral agent, who takes up the standpoint of impartiality in order to be just.<sup>21</sup> Thus, we cannot quickly infer from the absence of a particular feature of human life in the representation of the parties in a contract situation the further fact that this feature of human life is missing in the situation taken as a whole. We must look at the entire situation as it is modeled.

We should also note that contractarian theories adopt an implicit idea of the whole point of social cooperation. People will not cooperate unless there is some point to doing so, the idea goes. As David Hume puts it, there are certain circumstances, the “circumstances of justice,” in which choosing principles of justice has a point, and other circumstances where it would not have a point.<sup>22</sup> Rawls follows Hume here. The circumstances are, to put it very crudely, that people are so placed that they have both shared interests (such as an interest in cooperation, which makes life better for all) and also conflicts of interest that need to be resolved by principles of justice. These conditions, in turn, will only be met if people are in certain objective circumstances: occupying a definite territory that they must somehow share; vulnerable to attack; roughly similar in physical and mental powers, in the sense that no one of them can dominate all the others; and living under conditions of moderate scarcity. Rawls also draws attention to certain subjective circumstances: people must have roughly similar but at the same time complementary needs and interests, so that cooperation achieves something; they also have their own plans of life, and view their different conceptions of the good as deserving of recognition and respect. They also have various shortcomings of judgment and knowledge.<sup>23</sup> These features all play a role later on in determining the shape of the principles to which the parties will agree.

We must now launch into a rather detailed examination of the views of some of these thinkers, particularly Rawls. Although it might seem peculiar to suggest that such an academic book (and others like it) exercise a significant influence on public policy, I believe that it is not at all peculiar, given that Rawls’s book is simply the most refined and rigorous expression of a tradition that is long and deep in the entirety of Western thought. Theory gives people a set of terms with which to name themselves and describe what they are aiming at. If these theories contain defective images of the person and citizen, especially when

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<sup>21</sup> See references in my “Rawls and Feminism.”

<sup>22</sup> Hume D. *A Treatise of Human Nature*. bk. III, pt. II, sec. li.

<sup>23</sup> Rawls J. *A Theory of Justice*, pp. 126-7.

those defective images ride upon defects in existing popular thought, they can creep into people's minds as if they expressed reality itself, and dissident perspectives are less likely to be imagined. We can see, for example, that for many years theories of justice simply did not talk about the distribution of resources and opportunities within the family. This was itself a defect born of bad theorizing, although it is also the case that the bad theorizing grew out of defective ordinary thinking. But the prestige of theory can often make people feel that they are thinking well even when they are thinking badly; thus bad theory is even more dangerous than bad ordinary thinking, which tends to make less grandiose claims for itself. Thus in highlighting some of the defects in Rawls I am trying to pinpoint a place at which Western thought has typically gone wrong, and this place can be located with particular clarity in Rawls because his work is unusually well argued and systematic.

Let us now focus on just one feature of this account of the "circumstances of justice," shared by not only Hume and Rawls, but the entire social contract tradition. This feature is not directly implied by the assumption of rough similarity and non-domination, but it is a particular and controversial way of interpreting and further expanding that assumption. This is the fiction of competent adulthood. Whatever differences there are among the different founders of that tradition, all accept the basic Lockean conception of a contract among parties who, in the state of nature, are "free, equal, and independent."<sup>24</sup> Thus for Kant persons are characterized by both freedom and equality, and the social contract is defined as an agreement among persons so characterized. Contemporary contractarians explicitly adopt this hypothesis. For David Gauthier, people of unusual need are "not party to the moral relationships grounded by a contractarian theory."<sup>25</sup> Similarly, the citizens in Rawls's Well Ordered Society are "fully cooperating members of society over a complete life."<sup>26</sup>

Life, of course, is not like that. Real people begin their lives as helpless infants, and remain in a state of extreme, asymmetrical dependency, both physical and mental, for anywhere from ten to twenty years. At the other end of life, those who are lucky enough to live on into old age are likely to encounter another period of extreme dependency, either physical or mental or both, which may itself continue in some form for as much as twenty years. During the middle years of life, as we have already noted, many of us encounter periods of extreme dependency, some of which involve our mental powers and some our bodily

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<sup>24</sup> Locke J. *Second Treatise on Government*, ch. 8.

<sup>25</sup> Gauthier D. *Morals By Agreement*, New York, Oxford University Press, 1986, p. 18, speaking of all "persons who decrease th[e] average level" of well-being in a society.

<sup>26</sup> References to citizens as "fully cooperating" occur frequently in Rawls J. Dewey Lectures, "Kantian Constructivism in Moral Theory" (for example, p. 546) and in Rawls J. *Political Liberalism* (for example, p. 183).

## ETHICAL CHOICES IN LONG-TERM CARE

powers only, but all of which may put us in need of daily, even hourly, care by others. Finally, and centrally, there are many citizens who never have the physical and/or mental powers requisite for independence. Sometimes this lack of independence is caused by prevailing social arrangements, which could and should be changed: thus, Ten Broek's insistence that public space should be arranged in such a way that a blind person can get around in it.<sup>27</sup> Hence the demands of disabled workers that employers make reasonable accommodations so that they can work productively. Even these disabled citizens need special care, because the societies in which they live are not set up to offer them full independence. For still other citizens, the nature of the disability suggests that some type of asymmetrical dependence may need to be an ongoing feature of their lives. These citizens are dependent in different ways. Some have high intellectual capabilities but are unable, or deficiently able, to give and receive love and friendship; some are capable of love but unable to learn basic intellectual skills. (Many autistic people are in the former category; Kittay's cognitively disabled daughter is in the latter.) Some have substantial emotional and intellectual capabilities but in a form or at a level that requires special care. These lifelong states of asymmetrical dependency are in many respects isomorphic to the states of infants and the elderly.

In short, any real society is a caregiving and care-receiving society, and must therefore discover ways of coping with these facts of human neediness and dependency that are compatible with the self-respect of the recipients and do not exploit the caregivers.

Immanuel Kant's version of the social contract tradition, followed and extended by John Rawls,<sup>28</sup> is in many ways the most appealing strand in this tradition because it is the most deeply grounded in moral intuitions about respect and reciprocity that seem crucial to any good account of political principles for contemporary society. For Kant, the central guiding idea of ethics is that each human being is to be treated as an end in him or herself, and none as a mere means to the ends of others. Each has a dignity and none has merely a price in the market. This idea informs much that is fine in modern thinking in many traditions, and is the basis for thought about human dignity that informs many nations' constitutions and many international human rights documents.

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<sup>27</sup> See Silvers's introduction to Francis and Silvers, where she describes the indignity of having to wait outside a grocery store in the rain because the wheelchair entrance, required by law, was locked, allegedly to prevent shoplifting.

<sup>28</sup> This is not precisely the right way of putting it, because Rawls takes his departure from Kant's *ethical* writings, and develops a politics based on the core ideas of these, whereas Kant himself does not so clearly do that. His political doctrines have a more Hobbesian character than one might wish, despite his strong criticism of Hobbes.

The very first paragraph of the United Nations Charter, for example, announces a determination “to reaffirm faith in fundamental human rights, in the dignity and worth of the human person...” The first words of the Universal Declaration of Human Rights are: “Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world...” Jacques Maritain, one of the primary architects of the Universal Declaration, has spelled out the idea of dignity as implying that the human being has a worth and not just a price. He argues that people from many different religions and philosophical traditions can affirm this idea so long as they are prepared to say that the human being is not simply a tool of profit-making in the market.<sup>29</sup> Many contemporary constitutions include the idea of human dignity as a fundamental element, and it has teeth in judging that some practices are unacceptable.<sup>30</sup>

Kant's own version of the social contract doctrine thus looks very appealing, and it might lull us into thinking that we can use a contract doctrine without getting into any difficulties in the area of care. At this point, then, we need to probe more deeply, asking whether there are any features of this way of thinking that have not as yet been exposed to view that might be problematic, especially when we are thinking about the problem of care. And in fact, Kant's particular way of expressing his insights about human dignity is not unproblematic; in the particular area of care, a Kantian ethical starting point is indeed likely to give bad guidance. For Kant, human dignity and our moral capacity, dignity's source, are radically separate from the natural world. The human being is seen as a fundamentally split being, dignity housed by accident in an animal body. Morality certainly has the task of providing for human neediness, but the idea that we are at bottom split beings, both rational persons and animal dwellers in the world of nature, never ceases to influence Kant's way of thinking about how these deliberations about our needs will go.

What's wrong with the split? Quite a lot. First, it ignores the fact that our dignity just is the dignity of a certain sort of animal. It is the animal sort of dignity, and that very sort of dignity could not be possessed by a being who was not mortal and vulnerable, just as the beauty of a cherry tree in bloom could not be possessed by a diamond. Second, the split wrongly denies that animality itself can have a dignity; thus it leads us to slight aspects of our own lives that have worth, and to distort our relation to the other animals.<sup>31</sup> Third, it makes us think

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<sup>29</sup> Maritain. *Man and the State*, Chicago, University of Chicago Press, 1973, ch. 4, entitled, “Men Mutually Opposed in Their Theoretical Conceptions Can Come to a Merely Practical Agreement Regarding a List of Human Rights.”

<sup>30</sup> Germany is particularly active in this area, using the idea, for example, to criticize the treatment of women as commodities in pornographic performances: see my discussion in *Hiding From Humanity*, ch. 3.

## ETHICAL CHOICES IN LONG-TERM CARE

of the core of ourselves as self-sufficient, not in need of the gifts of fortune; in so thinking we greatly distort the nature of our own morality and rationality, which are thoroughly material and animal themselves; we learn to ignore the fact that disease, old age, and accident can impede the moral and rational functions, just as much as the other animal functions. Fourth, it makes us think of ourselves as a-temporal. We forget that the usual human life cycle brings with it periods of extreme dependency, in which our functioning is very similar to that enjoyed by the mentally or physically handicapped throughout their lives.

It is important to notice that the split goes wrong in both directions: it suggests, as I have said, that our rationality is independent of our vulnerable animality; it also suggests that animality, and non-human animals, lack intelligence, are just brutish and “dumb.” (For example, it suggests that activities such as athletics, dancing, sexual activity, and eating, are all unintelligent and brutish inasmuch as they are aspects of the nature that we share with the animals.) Both implications of the split should, of course, be called into question: in nature we find a rich continuum of types of intelligence and of practical capacities of many kinds; we cannot understand ourselves well without situating ourselves within that continuum.<sup>32</sup>

Political thought in the Kantian social-contract tradition (to stick with the part of the tradition I find deepest and most appealing) suffers from the conception of the person with which it begins. John Rawls’s contracting parties are fully aware of their need for material goods. Here Rawls diverges from Kant, building need into the foundations of the theory.<sup>33</sup> And Rawls denies that he has accepted the Kantian idea of the human being as a split being. But he departs from Kant only to a degree: for the parties are imagined throughout as competent

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<sup>31</sup> For one particularly valuable treatment of this theme, see Rachels J. *Created From Animals: The Moral Implications of Darwinism*, New York, Oxford University Press, 1990. Two wonderful pictures of the animal sort of dignity: Smuts B, untitled reply to Coetzee JM in Gutmann A, ed. *The Lives of Animals*, Princeton, Princeton University Press, 1999, and, my favorite, Pitcher G. *The Dogs Who Came to Stay*, New York, G. Putnam, 1995. I discuss the implications of recognizing the dignity of non-human animals in a review article about Wise SM. *Rattling the Cage: Toward Legal Rights for Animals*, Cambridge, MA, Perseus Books, 2000, forthcoming in *The Harvard Law Review*. See also MacIntyre A. *Dependent Rational Animals: Why Human Beings Need the Virtues*, Peru, IL, Open Court Publishing, 1999.

<sup>32</sup> See especially Rachels and MacIntyre (cited above).

<sup>33</sup> I do not mean to deny that Kant gives need an important role in his theory: for just one good treatment of this aspect of Kant’s thought, see Wood A. *Kant’s Ethical Theory*, Cambridge, Cambridge University Press, 1999. What I mean is that whereas for Kant personality and animality are conceptually independent, and personality is not itself understood in terms of need, for Rawls these two elements are more thoroughly integrated, and the person is understood from the first as in need of material and other goods. Rawls draws attention to this shift by calling his view an empirical type of Kantianism.

contracting adults, roughly similar in need, and capable of a level of social cooperation that makes them able to make a contract with others. Such a hypothesis seems required by the very idea of a contract for mutual advantage.

In so conceiving of persons, Rawls explicitly omits from the situation of basic political choice the more extreme forms of need and dependency human beings may experience. His very concept of social cooperation is based on the idea of reciprocity between rough equals and has no explicit place for relations of extreme dependency. Thus, for example, Rawls refuses to grant that we have any duties of justice to animals, on the grounds that they are not capable of reciprocity<sup>34</sup>; they are owed “compassion and humanity,” but “[t]hey are outside the scope of the theory of justice, and it does not seem possible to extend the contract doctrine so as to include them in a natural way”.<sup>35</sup> This makes a large difference to his theory of political distribution. For his account of the primary goods, introduced, as it is, as an account of the needs of citizens who are characterized by the two moral powers and by the capacity to be “fully cooperating,” has no place for the need of many real people for the kind of care we give to people who are not independent.<sup>36</sup>

Now of course Rawls is perfectly aware that his theory focuses on some cases and leaves others to one side. He insists that, although the need for care for people who are not independent is “a pressing practical question,” it may reasonably be postponed to the legislative stage, after basic political institutions are designed:

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<sup>34</sup> Rawls, J. *A Theory of Justice*, Cambridge, MA, Harvard University Press, 1971, pp. 17, 504-5.

<sup>35</sup> Rawls, J. *A Theory of Justice*, Cambridge, MA, Harvard University Press, 1971, p. 512.

<sup>36</sup> As Eva Kittay has argued in an excellent discussion (*Love's Labor*, pp. 88-99, and see also “Human Dependency and Rawlsian Equality,” in Meyers DT, ed. *Feminists Rethink the Self*, Boulder, Westview, 1997, pp. 219-66), there are five places in Rawls’s theory where he fails to confront facts of asymmetrical neediness that might naturally have been confronted. (1) His account of the “circumstances of justice” assumes a rough equality between persons, such that none could dominate all the others; thus we are not invited to consider relations of justice that might obtain between an adult and her infants, or her senile demented parents. (2) Rawls’s idealization of citizens as “fully cooperating” etc. puts to one side the large facts about extreme neediness I have just mentioned. (3) His conception of social cooperation, again, is based on the idea of reciprocity between equals, and has no explicit place for relations of extreme dependency. (4) His account of the primary goods, introduced, as it is, as an account of the needs of citizens who are characterized by the two moral powers and by the capacity to be “fully cooperating,” has no place for the need of many real people for the kind of care we give to people who are not independent. And (5) his account of citizens’ freedom as involving the concept of being a self-authenticating source of valid claims (e.g. *Political Liberalism* 32) fails to make a place for any freedom that might be enjoyed by someone who is not independent in that sense.

## ETHICAL CHOICES IN LONG-TERM CARE

So let's add that all citizens are fully cooperating members of society over the course of a complete life. This means that everyone has sufficient intellectual powers to play a normal part in society, and no one suffers from unusual needs that are especially difficult to fulfill, for example, unusual and costly medical requirements. Of course, care for those with such requirements is a pressing practical question. But at this initial stage, the fundamental problem of social justice arises between those who are full and active and morally conscientious participants in society, and directly or indirectly associated together throughout a complete life. Therefore, it is sensible to lay aside certain difficult complications. If we can work out a theory that covers the fundamental case, we can try to extend it to other cases later.<sup>37</sup>

This reply seems inadequate. Care for children, the elderly, and the mentally and physically handicapped is a major part of the work that needs to be done in any society, and in most societies it is a source of great injustice. Any theory of justice needs to think about the problem from the beginning, in the design of the most basic level of institutions, and particularly in its theory of the primary goods.<sup>38</sup> If we do not get clear about this problem at the most basic level, inadequate ways of thinking are bound to creep in later on— as they do when people raised in this general tradition discuss health financing, health savings, parental leave, and much else.

More generally, variations and asymmetries in physical need are simply not isolated or easily isolable cases; they are a pervasive fact of human life: pregnant or lactating women need more nutrients than non-pregnant persons, children need more protein than adults, and the very young and very old need more care than others in most areas of their lives. Even within the clearly recognized terrain of the “fully cooperating,” then, the theory of primary goods seems flawed if it does not take such variations into account in measuring who is and is not the least well off, rather than, as the theory recommends, determining that status by income and wealth alone.<sup>39</sup> Amartya Sen has used

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<sup>37</sup> Rawls J. Dewey Lectures, “Kantian Constructivism in Moral Theory,” *The Journal of Philosophy*, 1980, p. 546.

<sup>38</sup> See Kittay EF. *Love's Labor*, p. 77: “Dependency must be faced from the beginning of any project in egalitarian theory that hopes to include all persons within its scope.” For a remarkable narrative of a particular life that shows exactly how many social structures play a part in the life of a mentally handicapped child from the very beginning, see Bérubé M. *Life As We Know It: A Father, A Family, and An Exceptional Child*, New York, Vintage, 1996.

<sup>39</sup> This point has been repeatedly made by Amartya Sen in recommending an approach based on capability and functioning over the Rawlsian approach to primary goods; for the classic original statement, see Sen A. “Equality of What?,” in Sen A. *Choice, Welfare, and Measurement*, Oxford, Basil Blackwell, 1982, pp. 353-69; other good accounts of the approach are in Sen A. “Capability and Well-Being,” in Nussbaum M and Sen A, eds. *The Quality of Life*, Oxford, Clarendon Press, 1993, pp. 30-53; “Gender Inequality and Theories of Justice,” in Nussbaum M and Glover J, eds. *Women, Culture and Development*, Oxford, Clarendon Press, 1995, and *Inequality Reexamined*, New York, Russell Sage, 1992, esp. chs. 1, 3, 5.

the example of a person in a wheelchair, who will certainly need more resources to be fully mobile than will a person whose limbs work well.<sup>40</sup> With the same amount of income and wealth, this person will actually be much worse off than someone whose limbs work well.<sup>41</sup> Rawls can't consistently exclude this person, who surely has mental and moral powers. But even if he should exclude these physical disabilities, as some of his remarks suggest,<sup>42</sup> the problem of variation in need is pervasive. So even in order to take account of the physical needs of non-disabled citizens—which the theory seems bound, even on its own terms, to take account of<sup>43</sup>—Rawls will need a way of measuring well-being that does not rely on income and wealth alone, but looks at the abilities of citizens to engage in a wide range of human activities.

Thomas Scanlon, another major contemporary theorist in the Kantian social-contract tradition, confronts these problems facing a Kantian contract doctrine much more directly than does Rawls. I am unable here to discuss the subtleties of his view, which in any case is a moral and not a political contract doctrine, and which does not employ a hypothetical initial contract situation as does Rawls's theory. But, taking cognizance of the problem posed for such a theory by people with various disabilities, and by non-human animals, he concludes that we may recognize facts of extreme dependency in such a doctrine in one of two ways. Either we may persist in our pursuit of the contract doctrine and

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<sup>40</sup> Sen A. "Equality of What?"

<sup>41</sup> Two further problems not raised by Sen: First, even if we were to give more income and wealth to the person in a wheelchair, this would not solve the problem: for making this person mobile requires public action (construction of wheelchair ramps, accessible busses, etc.) that individuals cannot achieve on their own. Second, even if the person in the wheelchair were equally well off with regard to economic well-being, there is a separate issue of dignity and self-respect. By measuring relative social positions by income and wealth alone, Rawls ignores the possibility that a group may be reasonably well-off economically, but suffer grave disabilities with regard to the social bases of self-respect. One might argue that gays and lesbians in our society are in precisely that position; but certainly the physically and mentally handicapped will be in that position, unless society makes a major and fundamental commitment to inclusion and respect.

<sup>42</sup> At times, as in the passage from the Dewey Lectures, "Kantian Constructivism in Moral Theory," cited in the text above, Rawls suggests leaving aside all severe or expensive physical illness, as well as mental disability: see also *Political Liberalism*, p. 272 n. 10. At other times (e.g. *Political Liberalism*, p. 302) he treats possession of the two moral powers as a sufficient, as well as a necessary, condition of fully cooperating status.

<sup>43</sup> Rawls proposes taking account of it at the legislative stage: see *Political Liberalism*, pp. 183-6; but given the pervasive role of political institutions in shaping the life chances of such citizens from the very beginning of a human life, this seems an inadequate reply. The concrete strategems adopted to address issues of disability (laws mandating wheelchair ramps, laws such as the Individuals with Disabilities Education Act) could well be left until this stage; but the fact that citizens experience such needs for care must be recognized from the start, and a commitment made to address these concerns.

## ETHICAL CHOICES IN LONG-TERM CARE

say that the contracting parties are also trustees for those who are incapable of participating in that process; or we may say that the contract doctrine offers an account of only one part of morality: we will need a different account to cope with the facts of extreme dependency.<sup>44</sup> Applied to the Rawlsian project of selecting principles of justice that will form the basic structure of society,<sup>45</sup> this would mean that we either take the parties in the Original Position to be trustees for the interests of all dependent members of society, as they currently are trustees for future generations—or else we should grant that the Original Position is not a complete device for designing political justice, and that other approaches are also required.

The first solution seems unsatisfactory. To make the “fully cooperating” trustees in a hypothetical original situation slights the dignity of physically and mentally handicapped people, suggesting that they are worthy of respect in the design of basic political institutions only on account of some relationship in which they stand to so-called “fully cooperating” people. The bargain, after all, is a bargain for mutual advantage, and it assumes a rough equality among its participants; the dependents enter the bargain not because they are equipped to participate in such a bargain, but only because a contracting party cares about their interests. Furthermore, the move also means making the “fully cooperating” trustees for their own infancy and senility, and perhaps other stages of their own lives. David Gauthier puts the problem most starkly, when he says that the elderly have paid for their care by earlier periods of productive activity, but the handicapped have not.<sup>46</sup> In other words, for the contractarian only productivity justifies, ultimately, a claim to support, and the elderly get support only because at one time they were not elderly. Animality and human neediness on their own cannot justify a claim to support. Rawls’s theory, though more subtle than Gauthier’s, still suffers from something like this problem. To require of the parties that they split their thinking in this way, conceiving of themselves as made up of two parts, the rational being and the natural organism, is to force into their thinking a Kantian splitting that may well prejudice their thoughts about the dignity of the animal organism in themselves. They will be encouraged to think of it as a drag on personhood and on the advantages people seek when they make a cooperative bargain for mutual advantage.<sup>47</sup> Rawls thus reinforces prevalent

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<sup>44</sup> Scanlon, *What We Owe to Each Other*, Cambridge, MA, Harvard University Press, 1999, pp. 177-87. I am very grateful to Scanlon for correspondence that makes the complexity of his approach to these cases clear. Because this is a paper about the basic structure of a political conception, I shall hope to take up his views elsewhere.

<sup>45</sup> Once again, it is very important to stress the fact that this is Rawls’s project, not Scanlon’s, and that Scanlon does not recommend applying it in this way.

<sup>46</sup> *Morals by Agreement*, p. 18 n. 30.

<sup>47</sup> The interweaving of Kantian and contractarian elements in Rawls’s theory is very complicated, and I cannot further dissect it here; I do so in the second of my Tanner Lectures, “Beyond the Social Contract: Toward Global Justice,” to be delivered at Australian National University, November 2002.

social attitudes that have real political influence. Are we not in effect saying that animality gets support only in virtue of its contingent link to “fully cooperating” adulthood? And doesn’t this slight the dignity and worth that needy human animals surely possess even when they are not fully cooperating? Surely, if it is not necessary to require such split thinking, we should avoid it.

Thus I prefer Scanlon’s second solution: the contract doctrine, while an excellent model for many aspects of our moral relations, does not provide a complete ethical theory. But this reply, which would be fine for Scanlon because he is talking about ethical rather than political theory, employs no hypothetical initial situation, and makes no claims to completeness, creates large problems for the contract doctrine in the area of political theory. Any approach to the design of basic political institutions must aim at a certain degree of completeness and finality, as Rawls’s doctrine explicitly does.<sup>48</sup> Thus, although it is very reasonable to think that political principles are also ethical, not all ethical principles are suitable for political thinking; they have to be the type of principle that can be put to work in designing something people actually live by. In this case, Rawls’s parties are designing the basic structure of society, those institutions that influence all citizens’ life-chances pervasively and from the start. So it is not open to us to say: we have done one part of that task, but of course other parts, equally basic, based on completely different principles, will come along later. If we leave for another day not only our relations to the non-human animals but also the needs entailed by our own animality, that would leave huge areas of political justice up for grabs and would entail the recognition of much indeterminacy in the account of basic justice as so far worked out.

What, then, can be done to give the problem of care and dependency sufficient prominence in a theory of justice? The first thing we might try, one that has been suggested by Eva Kittay in her fine book, is to add the need for care during periods of extreme and asymmetrical dependency to the Rawlsian list of “primary goods,” goods that all citizens need to carry out their plans of life, whatever they are. To add care to such a list amounts to judging that care is among the basic needs of citizens.<sup>49</sup> In making this modification, citizens would be recognizing that these periods of dependency are part of the facts of human life, against which they would wish to insure themselves. There is no barrier in contract doctrine as such to making such a modification. Notice, however, that in order to make such a modification while retaining the basic framework of the

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<sup>48</sup> See for example Rawls J. *A Theory of Justice*, p. 135, where finality is a formal condition on political principles, and pp. 175-8, in the argument for the two principles where it is made clear that the agreement “is final and made in perpetuity” and that “there is no second chance” (p. 176). Rawls’s opposition to intuitionism focuses on this issue: see for example *A Theory of Justice*, pp. 35-6.

<sup>49</sup> Kittay EF. *Love’s Labor*, pp. 102-3.

## ETHICAL CHOICES IN LONG-TERM CARE

contract doctrine, we would need to make a sharp split between two cases that I have suggested actually lie on a continuum: the case of the childhood and old age of the “normal” “independent” human adult, and the case of lifelong mentally or physically disabled human beings.<sup>50</sup> This sharp division of two closely related cases is most unfortunate. It is the basis for much social prejudice, which typically proceeds from a sharp division between the “normal” and various people who are taken to be somehow “spoiled,” and encourages the stigmatization of the latter.<sup>51</sup>

If we add care to the list of primary goods, we would be led to make another modification in the Rawlsian theory, for care is hardly a commodity, like income and wealth, to be measured by the sheer amount of it citizens have. Thus adding care to the list would cause us to notice that Rawls’s list of primary goods is already quite heterogeneous in its structure. Some of its members are thing-like items such as income and wealth; but some are already more like human capabilities that function in various ways: the liberties, opportunities, and powers, and also, as we have noted, the social basis of self-respect. Along with this suggestion, we might propose understanding the entire list of primary goods as a list not of things but of basic capabilities.<sup>52</sup> This change would not only enable us to deal better with people’s needs for various types of love and care as elements of the list, but would also answer the point that Sen has repeatedly made all along about the unreliability of income and wealth as indices of well-being. The well-being of citizens will now be measured not by the sheer amount of income and wealth they have, but by the degree to which they have the various capabilities on the list. For example, one might be well off in terms of income and wealth and yet unable to function well in the workplace because of burdens of caregiving at home.<sup>53</sup> Looking at capability rather than at resources gives us a much more accurate sense of what people are actually able to do and to be—as the *Human Development Reports* have long recognized when they use capabilities as the basis for quality-of-life comparisons across societies.

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<sup>50</sup> For more discussion of this continuum and a critique of the idea of the “normal,” see my *Hiding From Humanity: Disgust, Shame, and the Law*, Princeton University Press, forthcoming, 2003, ch. 5.

<sup>51</sup> See Erving Goffman’s classic work *Stigma: Notes on the Management of Spoiled Identity*, New York, Simon & Schuster, 1963, and my discussion of his ideas in *Hiding From Humanity: Disgust, Shame, and the Law*, chs. 4 and 5.

<sup>52</sup> Like Sen, I defend this idea, in *Women and Human Development: The Capabilities Approach*, Cambridge and New York, Cambridge University Press, 2000, ch. 1; unlike Sen, I propose an actual list of the central capabilities, analogous to primary goods. *Women and Human Development*, ch. 1 discusses in detail the relationship of my approach to Rawls’s.

<sup>53</sup> On this point see especially Williams. *Unbending Gender* (cited above).

If we accepted these two changes, we would surely add a third, highly relevant to our thoughts about infancy and old age. We would add other capability-like items to the list of basic goods: for example, the social basis of health, and the social basis of imagination and emotional well-being.<sup>54</sup> Although I have said that the goal of this paper is to advance a conception that can command broad agreement, not a controversial idiosyncratic theory, it seems obvious that the need for health, for education that stimulates the imagination, for emotional security, and for access to leisure and play are human goods recognized widely all over the world and in international human rights instruments. We cannot fully say what is wrong with current arrangements regarding care without extending the list of “primary goods” in this way; for often the most efficient woman, who manages to juggle job and care responsibilities, still loses out, by being unable to enjoy leisure activities or by bearing a high load of emotional stress that is incompatible with health.

Suppose, then, we do make these three changes in the list of primary goods: we add care in times of extreme dependency to the list of primary goods; we reconfigure the list as a list of capabilities; and we add other pertinent items to the list.<sup>55</sup> Have we done enough to salvage the contract doctrine as a way of generating basic political principles? I believe that there is still room for doubt. Consider the role of primary goods in Rawls’s theory. The account of primary goods is introduced in connection with the Kantian political conception of the person, as an account of what citizens characterized by the two moral powers need.<sup>56</sup> Thus, we have attributed basic importance to care only from the point of view of our own current independence. It is good to be cared for only because care subserves moral personality, understood in a Kantian way as conceptually quite distinct from need and animality. This seems like another, more subtle way of making our animal nature subserve our human nature, where humanity is understood to exclude animality. The idea is that because we are dignified beings capable of political reciprocity, therefore we had better provide for times when we are not that, so we can get back to being that as quickly as possible. I think that this is a dubious enough way to think about illnesses in the prime of life; but it surely leads us in the direction of a contemptuous attitude toward infancy and childhood, and, a particular danger in our society, toward elderly

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<sup>54</sup> See my discussion of this point in *Women and Human Development*, ch. 1.

<sup>55</sup> In Tanner Lecture 2, I argue that Rawls has good reasons internal to his theory for refusing to accept these modifications.

<sup>56</sup> In *A Theory of Justice* primary goods were characterized as all-purpose means to the pursuit of one’s own conception of the good, whatever it is; in the Dewey Lectures, “Kantian Constructivism in Moral Theory,” and in *Political Liberalism*, the interpretation shifts, and Rawls acknowledges that they are means with regard to the Kantian political conception of the person: see *Political Liberalism*, pp. 187-90.

## ETHICAL CHOICES IN LONG-TERM CARE

disability. Once again, this is just a philosophical book, but theory does influence practice, particularly when it rests upon and further reinforces defective conceptions that are very widespread.

Next, it leads us strongly in the direction of not fully valuing those with lifelong mental disabilities: somehow or other, care for them is supposed to be valuable only for the sake of what it does for the “fully cooperating.” They are not really part of the bargaining structure, and their needs, like the needs of non-human animals, will be taken care of only after the basic structure of society is already designed. They are, it would seem, being used as means for someone else’s ends, and their full humanity is still being denied. Finally, as I have mentioned, the very positing of a sharp split between “normals” and people with a “spoiled identity” is central to the operations of much pernicious social prejudice, particularly prejudice directed against the disabled.<sup>57</sup>

So I believe that we need to delve deeper, redesigning the political conception of the person, bringing the rational and the animal into a more intimate relation with one another, and acknowledging that there are many types of dignity in the world, including the dignity of mentally disabled children and adults, the dignity of the senile demented elderly, and the dignity of babies at the breast. We want the picture of the parties who design political institutions to build these facts in from the start. The kind of reciprocity in which we humanly engage has its periods of symmetry, but also, of necessity, its periods of more or less extreme asymmetry—and this is part of our lives that we bring into our situation as parties who design just institutions. And this may well mean that the theory cannot be a contractarian theory at all.

Such a conclusion should be reached with caution. Rawls’s theory, as I mentioned at the opening of this section, has often been wrongly criticized because critics have not noticed that his model of the person in the Original Position is complex. His account of the person is not simply the account of the rationality of the parties, but that account *combined with* the account of the veil of ignorance, which is a complex way of modeling benevolence. Thus it is incorrect to say that he has not included concern for others in the conception of the person that forms the foundation of his theory—as he has noted, discussing Schopenhauer’s similar critique of Kant.<sup>58</sup> What this mistake shows us is that the contract doctrine has many ways of modeling the person; so we should not rule out the possibility that some device may be found through which

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<sup>57</sup> I take the term “spoiled identity” from Erving Goffman’s classic *Stigma: Notes on the Management of Spoiled Identity*, New York, Simon and Schuster, 1963, discussed at length in my *Hiding From Humanity*. It means that a person is regarded as tainted, less than fully human; and Goffman observes that all people’s dealings with a person who has a stigmatized trait tend to revolve around the disability; the person’s full individuality and humanity are denied.

a doctrine basically contractarian in spirit could model need and animality, just as it has modeled benevolence.<sup>59</sup> There is, however, some reason to doubt that this can be done. For any such model would still involve a split of just the sort to which I have objected, one that makes our rationality trustee, in effect, for our animality. And that, as I've argued, is inadequate for the kind of dignity and centrality we want to give to the problems of asymmetrical need.

Thus, while not denying that some determined contractarian might possibly solve this problem, I think it best to proceed as if it has not been solved. When we add to our worries the fact that Rawls's contract doctrine uses a political concept of the person at a number of different points, most of them not in association with the complex model of the original position, we have even more reason to want the political concept of the person to be one that does justice to temporality and need.

We have gone into some rather abstruse details of philosophy. But, as my references to the *Human Development Reports* indicate, development paradigms and other public policy paradigms are profoundly influenced by philosophical traditions, in much the way that the constitutions of nations are influenced by the theoretical framework of their founders. If we want to get at what is wrong and what needs fixing, we need to delve deeply into these matters, for it is not enough to tinker with outcomes; we need to correct the misleading deep pictures that have led to the inadequate outcomes. Ideas of independence, productivity, and the exchange of one person's contribution for another are deeply rooted in our popular thinking; at one time philosophical ideas, they have become widespread political ideas, and they are further disseminated by the guiding role of economics, a discipline that took root in the soil of social contract thinking. We often use such ideas without even realizing that they have a pedigree, and this means without examining the problematic aspects of that pedigree. If we are more alert, we are likely to be more in control of our language and where it leads us. Certainly it should not lead us to the traditional practices of neglecting care as a social problem, devaluing the work of caregiving, and shortchanging the needs of people who need care.

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<sup>58</sup> I discuss this issue in detail in "Rawls and Feminism," with respect to both Rawls's text and the most prominent feminist critiques. See, for example, Benhabib S. "The Generalized and the Concrete Other," in *Situating the Self*, pp. 148-77; Friedman M. *What Are Friends For? Feminist Perspectives on Personal Relationships and Moral Theory*, Ithaca, Cornell University Press, 1993.

<sup>59</sup> I owe this point to Geoffrey Sayre-McCord, who pointed out that I myself have criticized feminists who don't see the veil of ignorance as part of the model of the person: see "Rawls and Feminism."

## ETHICAL CHOICES IN LONG-TERM CARE

### A.4 BEYOND THE SOCIAL CONTRACT

The social contract tradition has, I have argued, some grave problems. On the other hand, it also has some important virtues that we must not lose sight of in trying to reform it. In particular, the ideas of reciprocity and equality it contains are deeply attractive ideas for a modern society. The idea that political principles express mutual respect for human dignity, agency, and inviolability is another idea to which we should cling. Let us see, then, where the gravest problems in the tradition seem to lie, and let us see whether we can propose a reform of it that would not lose hold of these highly attractive insights.

In order to place the problems of care and dependency in the right political perspective, giving them adequate salience and recognizing their importance for political justice, we need, then, to make three modifications in the dominant tradition. We need, first, a richer account of the “primary goods” a just society distributes, goods that can be expected to be of value in any life plan that citizens choose to pursue.<sup>60</sup> This list should include a number of items that Rawls currently omits, including health care, leisure, and education; but it must prominently include care in times of acute dependency. Because the Rawlsian list of primary goods (and my own list of capabilities) also includes the social basis of self-respect as a primary good, we will understand that the care citizens have a right to, as a basic entitlement, is care that is compatible with the self-respect of the recipient. Because the list I favor will also include the entitlement to leisure for play and the cultivation of one’s faculties, political participation, and employment opportunities, we will understand that this care must be such as to protect the caregivers against exploitation that cripples their access to these other primary goods.<sup>61</sup>

The second modification that we need to make is to conceive of the whole project of distributing primary goods not in terms of resources simply, but in terms of fostering a wide range of (interlocking and mutually supportive) human capabilities. Both Sen and I argue that, particularly when we are addressing entrenched privilege and hierarchy, the perspective supplied by the capabilities approach is superior to those supplied by the more traditional focus on resources and on utility. We have not satisfied the demands of this

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<sup>60</sup> Rawls has interpreted the idea of primary goods differently over time: in *A Theory of Justice* he understands them as all-purpose means to whatever ends they may have; in the Dewey Lectures, “*Kantian Constructivism in Moral Theory*,” and in *Political Liberalism*, he argues, instead, that they are to be understood in close connection with the Kantian constructivist conception of the person, as things people endowed with the “two moral powers” would reasonably believe they need to have. I discuss my own approach to the issue of primary goods in *Women and Human Development*, ch. 1.

<sup>61</sup> See Daly M, ed. *Care Work: The Quest for Security*, Geneva, International Labor Office, 2001.

approach unless and until we have brought all citizens up to a specified level of ability actually to choose to perform the functioning in question, and we easily see that citizens differently placed may need differing amounts of resources in order to arrive at the desired level of capability.

A shift to the capabilities perspective delivers several further dividends, which can be only briefly discussed here. First, such an approach dovetails nicely with the emphasis on empowerment and opportunity in many constitutional traditions of the world; it provides a nice way of thinking about what basic constitutional entitlements are all about.<sup>62</sup> Second, the focus on capabilities assists us greatly in thinking about the entitlements of nonhuman animals. Indeed, I would argue that the capabilities approach ultimately provides a basis for approaching this difficult question that is superior to the bases supplied by Utilitarianism, the social contract tradition, and even rights-based approaches.<sup>63</sup>

Third, and crucially, the capabilities approach is not restricted to the nation state, as the social contract approach traditionally has been. The thought experiment of the social contract tradition is that of a group of people who are choosing principles by which to live together in a single society. Typically, it is envisaged as a process that leads to the choice of a constitution for the society in question. For this reason, it has been extremely difficult for thinkers in this tradition to think productively about relations between nations, and this thought has almost always taken the form of thinking about how nations bargain with one another over matters of security and (occasionally) basic human rights. The idea of material entitlements that require redistribution from richer to poorer nations has simply been off the agenda of the tradition. But social protection in the areas of child care, disability care, and elder care needs to be thought about in a way that prominently raises questions about what nations owe to one another. The world is no longer the world of the isolated nation-state (if it ever was). It is a complex interlocking structure in which nations, international agencies, corporations, NGOs, and individuals are all active. An approach that begins from the goal of securing to all human beings the basic capability entitlements I have described, and that then asks how this is to be done, through what combined activity of all these agents, seems to offer better guidance than the contract paradigm.<sup>64</sup>

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<sup>62</sup> See my “Capabilities as Fundamental Entitlements: Sen and Social Justice,” forthcoming in *Feminist Economics*; and “Constitutions and Capabilities,” forthcoming in volume ed. by Deen Chatterjee, Rowman and Littlefield.

<sup>63</sup> See my “Animal Rights: The Need for a Theoretical Basis,” *Harvard Law Review*, 2001, 114:1506-49.

<sup>64</sup> See my “Women and the Law of Peoples,” forthcoming in *Philosophy, Politics, and Economics*, and my Tanner Lectures for 2002, “Beyond the Social Contract: Capabilities and Social Justice,” forthcoming.

## ETHICAL CHOICES IN LONG-TERM CARE

Finally, we need a new conception of the person for purposes of institutional design, one that does not sharply split off human dignity from human need and animality. Why should this be so very important, one might ask? What do economic and political arrangements have to do with something so abstract as a “conception of the person”? Here, I believe, we must grant that many factors shape the way citizens see their political project and themselves as actors in it. But the tradition of theorizing in the social contract tradition, which has been very widely disseminated in Western politics, law, and economics, has surely had a very deep influence on the way people see one another as political actors. Even when people have no awareness of the particular texts of the tradition, the idea of the citizen as an independent bargainer, who pays for the benefits he gets by his own productive contributions, is a daily part of our lives.

So I believe we need to adopt a political conception of the person that has its sources in many different traditions, but that, in terms of the Western tradition, is more Aristotelian than Kantian.<sup>65</sup> This conception sees the person from the start as both capable and needy—“in need of a rich plurality of life-activities,” to use Marx’s phrase, whose availability will be the measure of well-being. Such a conception of the person, which builds growth and decline into the trajectory of human life, will put us on the road to thinking well about what society should design. We don’t have to contract for what we need by producing; we have a claim to support in the dignity of our human need itself. Since this is not just an Aristotelian idea, but one that corresponds to human experience, there is good reason to think that it can command a political consensus in a pluralistic society. If we begin with this conception of the person and with a suitable list of the central capabilities as primary goods, we can begin designing institutions by asking what it would take to get citizens up to an acceptable level on all these capabilities.

In *Women and Human Development* I therefore proposed that the idea of central human capabilities be used as the analogue of Rawlsian primary goods, and that the guiding political conception of the person should be an Aristotelian/Marxian conception of the human being as in need of a rich plurality of life-activities, to be shaped by both practical reason and affiliation. I argue that these interlocking conceptions can form the core of a political conception that is a form of political liberalism, close to Rawls’s in many ways. The core of the political conception is endorsed for political purposes only, giving citizens a

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<sup>65</sup> As the late Peter Cicchino eloquently put this point, Aristotle’s conception is not deductive or *a priori*: it respects widely held views about human reality, but takes experience as its source and guide. Second, it takes seriously the materiality of human beings—their need for food, shelter, friendship, care, what might be called their basic dependency. Third, it is epistemologically modest—it does not claim to have the exactitude of mathematics, but rather is content to look for ‘such precision as accords with the subject-matter.’” Cicchino P. “Building on Foundational Myths: Feminism and the Recovery of ‘Human Nature’: A Response to Martha Fineman,” *American University Law Review*, 1999.

great deal of space to pursue their own comprehensive conceptions of value, whether secular or religious. Yet more room for a reasonable pluralism in conceptions of the good is secured by insisting that the appropriate political goal is capability only: citizens should be given the option, in each area, of functioning in accordance with a given capability or not so functioning. To secure a capability to a citizen it is not enough to create a sphere of non-interference; the public conception must design the material and institutional environment so that it provides the requisite affirmative support for all the relevant capabilities.<sup>66</sup> Thus care for physical and mental dependency needs will enter into the conception at many points, as part of what is required to secure to citizens one of the capabilities on the list.<sup>67</sup>

In most cases, we can think well about the needs of mentally disabled children and adults by adopting a specification of a general capability that is appropriate for their needs. A 1997 law in the U.S., the Individuals with Disabilities Education Act, holds that each child with a disability is entitled to a “suitable education” in the “least restrictive environment possible.” What this will be is to be determined by an individual conference among school, child, and parents, which results in an “Individualized Education Plan,” one suited to develop that child’s particular powers of mind and thought. This seems to be, in effect, a capability approach, or, to put it in other words, a Human Development perspective. At times, we may need to qualify the capability goal with reference to the particular type of disability in question. Thus for many children with Down Syndrome, it will be reasonable to expect that they can participate in political society and learn to express their political convictions.<sup>68</sup> For Kittay’s daughter, by contrast, who will never speak and whose cognitive level will remain at a “low” level, political capabilities will need to be mediated through appropriate guardianship. In general, however, the aim ought to be to deliver all of the capabilities to all citizens, at some appropriate level and in some way.

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<sup>66</sup> In that way my view is close to the type of liberalism defended (against Lockean contractarianism) by T. H. Green, though my form is not perfectionistic, but is, rather, a form of political liberalism. I have found very illuminating the discussion of the liberal tradition in Deigh J. “Liberalism and Freedom,” in Sterba JP, ed. *Social and Political Philosophy*, London and New York, Routledge, 2001, pp. 151-66.

<sup>67</sup> I attach the current version of the capabilities list at the end of this paper. The view is further debated in a symposium on my political philosophy in *Ethics*, Fall 2000; see in particular the paper by Richard Arneson, which takes me up on the question of capability and functioning, arguing that a more robust perfectionism that makes actual functioning the goal is required in areas such as health. I dispute this, defending my form of political liberalism, in “Aristotle, Politics, and Human Capabilities: A Response to Antony, Arneson, Charlesworth, and Mulgan,” *Ethics* 111 (2000), pp. 102-40.

<sup>68</sup> Levitz and Kingsley, and Bérubé, cited above. I discuss these cases in “Disabled Lives: Who Cares?” *The New York Review of Books*, January 11, 2001, 48:34-37. I discuss the Individuals with Disabilities Education Act in *Hiding From Humanity*, ch. 5.

## ETHICAL CHOICES IN LONG-TERM CARE

My solution to these problems focuses on the importance of giving each and every citizen a set of capabilities that they can use to fashion lives for themselves. It thus lies squarely within the tradition of Western liberal political thought, although it involves a more social and interrelational conception of the person than do many types of liberalism, and although it insists more than many on the material prerequisites of human liberty.<sup>69</sup> Ideas of respect for human dignity are as central to my approach as they are for Kant and his modern descendants, although I conceive of dignity in a subtly different, and more “embodied” way.<sup>70</sup>

But Eva Kittay suggests that we should go further, departing from all forms of the liberal tradition. She holds that Western political theory must be radically reconfigured to put the fact of dependency at its heart. The fact, she says, that we are all “some mother’s child,” existing in intertwined relations of dependency, should be the guiding image for political thought.<sup>71</sup> Such a care-based theory, she thinks, will be likely to be very different from any liberal theory, since the liberal tradition is deeply committed to goals of independence and liberty. Although Kittay supplies few details to clarify the practical meaning of the difference, I think her idea is that the care-based theory would support a type of politics that provides comprehensive support for need throughout all citizens’ lives, as in some familiar ideals of the welfare state—but a welfare state in which liberty is far less important than security and well-being.

Kittay is not altogether consistent on this point. At times she herself uses classic liberal arguments, saying that we need to remember that caregivers have their own lives to lead, and to support policies that give them more choices.<sup>72</sup> But on the whole she rejects, in the abstract, solutions that emphasize freedom as a central political goal. The concrete measures she favors do not seem to have such sweeping anti-liberal implications: thus, she supports the restoration and expansion of Aid to Families with Dependent Children, a program that gave crucial assistance to poor families; she supports expansion of the Family and Medical Leave Act of 1993, which provided limited, though still inadequate, guarantees of leave for family care and medical problems; and

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<sup>69</sup> Such ideas are also associated with the thought of T. H. Green, one of the earliest champions of public education for all children, whose thought reflected, similarly, a combination of liberal and neo-Aristotelian elements.

<sup>70</sup> For argument that the liberal tradition is not inherently wedded to a pernicious form of egoism or denial of communal and relational values, see my “The Feminist Critique of Liberalism,” ch. 2 of *Sex and Social Justice*, New York, Oxford University Press, 1999.

<sup>71</sup> Kittay EF. *Love’s Labor*, ch. 1. Part III, on political strategies, is entitled “Some Mother’s Child.”

<sup>72</sup> For passages that focus on the need of the individual for choice and independence, see for example pp. 34-5, 53, 98, 192 n. 32.

she supports various educational measures promoting the dignity of the disabled, through a judicious combination of “mainstreaming” and separate education.<sup>73</sup> All these are familiar liberal policies, which combine support for need with an emphasis on choice and liberty as important social goals. Kittay’s most controversial proposal, as I have already mentioned, is that of a direct non-means-tested payment to those who care for family dependents at home. This very interesting proposal clearly has, or could have, a liberal rationale: that of ensuring that these people are seen as active, dignified workers rather than passive non-contributors.

Indeed, if we adopt all the changes I have proposed, we will still have a theory that is basically liberal. For theories that take their start from an idea of human capability and functioning emphasize the importance of giving all citizens the chance to develop the full range of human powers, at whatever level their condition allows, and to enjoy the sort of liberty and independence their condition allows. Sen even speaks of “the perspective of freedom” as the animating ideal of the Human Development paradigm.<sup>74</sup> Would we do better to reject this theory in favor of Kittay’s idea, rejecting independence as a major social goal and conceiving of the state as a universal mother? To be sure, nobody is ever self-sufficient; the independence we enjoy is always both temporary and partial, and it is good to be reminded of that fact by a theory that also stresses the importance of care in times of dependency. But is being “some mother’s child” a sufficient image for the citizen in a just society? I think we need a lot more: liberty and opportunity, the chance to form a plan of life, the chance to learn and imagine on one’s own.

These goals are obviously crucial for caregivers. But they are also crucial for the recipients of care. Ten Broek and other advocates for the physically disabled emphasize the great importance of access to public space, the freedom to occupy the world on a basis of equality with others. Kingsley and Levitz insist that these goals are of central importance to them as well, as people with Down Syndrome; they want to participate in political life, to write a book (as they did), to have their own voice respected. Kittay’s daughter Sesha is not in this category, because of her profound cognitive impairment. But although Sesha will never live on her own (and although Kittay is right to say that independence should not be seen as a necessary condition of dignity for all mentally disabled

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<sup>73</sup> Kittay EF. *Love’s Labor*, ch. 5.

<sup>74</sup> In my *Feminist Economics* paper (cited above), I argue that this goes too far: for not all freedoms are in fact good: the freedom of businesses to pollute the environment, the freedom of men to harass women in the workplace, etc. Any society that pursues freedom also has to evaluate freedoms, saying which are and are not core social goals. Of the rest, some (for example the freedom of motorcyclists to ride around without a helmet) may be simply trivial. Others (the ones I just mentioned) may be positively bad, and should be limited by law.

## ETHICAL CHOICES IN LONG-TERM CARE

people),<sup>75</sup> many others do aspire to hold a job, and vote, and tell their own story. Michael Bérubé ends his compelling account of his son's life with the hope that Jamie, too, will write a book about himself, as Levitz and Kingsley did.<sup>76</sup> One day Jamie's kindergarten class went round the room, asking the children what they wanted to be when they grew up. They said the usual things: basketball star, ballet dancer, fireman. The teacher wasn't sure Jamie would understand the question, so she asked it very clearly. Jamie just said, "Big." And his literal answer, said the teacher, taught them all something about the question. Bérubé too wants, simply, a society in which his son will be able to be "big": healthy, educated, loving, active, seen as a particular person with something distinctive to contribute rather than as "a retarded child."

For that to happen, his dependencies must be understood and supported. But so too must his need to be distinct and an individual, and at this point Bérubé refers sympathetically to Rawls. He argues that the idea at the heart of the Individuals with Disabilities Education Act—the idea that every child has the right to an "appropriate education" in the "least restrictive environment" possible, based on an "Individualized Education Plan"—is a profoundly liberal idea, an idea about individuality and freedom. One of the most important kinds of support mentally disabled children need is the support required to be free choosing adults, each in his or her own way. Insofar as Kittay suggests that we downplay or marginalize such liberal notions in favor of a conception of the state that makes it the parental supporter of its "children's" needs, I think she goes too far, misconceiving what justice would be for both the disabled and the elderly. Even for Sessa, who will never vote or write, doesn't a full human life involve a kind of freedom and individuality, namely, a space in which to exchange love and enjoy light and sound, free from confinement and mockery?

So I believe that the problem we have investigated shows us that liberal theory needs to question some of its most traditional starting points—questioning, in the process, the Kantian notion of the person. But that does not disable liberalism; it just challenges us all to produce a new form of liberalism, more attentive to need and its material and institutional conditions. The liberal ideas of freedom and of the human need for various types of liberty of action are precious ideas that feminist philosophers, it seems to me, should cherish and further develop, creating theories that make it possible for all citizens to have the support they need for the full development of their human capabilities.

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<sup>75</sup> See Kittay EF. *Love's Labor*, ch. 6, a beautiful and lucid account of her daughter's life.

<sup>76</sup> Bérubé M. *Life As We Know It*, p. 264: "For I have no sweeter dream than to imagine— aesthetically and ethically and parentally—that Jamie will someday be his own advocate, his own author, his own best representative."

If we choose the capabilities approach rather than the social contract approach, we have no difficulty developing political principles that show respect for the disabled as fully equal citizens. At the same time, such an approach, as I have argued, does a superior job of conceptualizing claims of justice that arise in connection with the care of children and elderly people. Their asymmetrical needs are treated as part of their human dignity, rather than as large social costs to be borne.

Although in both theory and practice the nations of the world have moved beyond earlier versions of the social contract tradition, by insisting on human dignity as a central social value in international human rights instruments and many national constitutions, we have not yet altogether shaken off a dark implication inherent in the very idea of a social bargain for mutual advantage, namely, that those who are dependent and “unproductive” are not full participants.<sup>77</sup> “A more capacious and supple sense of what it is to be human”<sup>78</sup> is crucial if we are to deliberate well about these problems of justice.

One reason for optimism, as Bérubé says, is that we know that human beings are able to imagine, and to communicate what they imagine, even to someone who did not have that image before. If we were able to form the old picture that divided society into the “independent” and “productive” and the helpless “unproductive,” it ought to be possible to learn to think of ourselves as beings both capable and disabled, in need of support for a rich plurality of life activities. We need to insist that conceptual foundations matter, and that the reflection on such foundations should be profoundly ethical, asking what pictures are worthy of us, as human beings who are trying to live together with justice. Economic paradigms are important for implementing any goals we articulate, but those paradigms cannot tell us who we are and where we are going. Ethical reflection is needed if we are to do this job well.

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<sup>77</sup> Thus Gauthier says that while the elderly have paid for the care they receive by earlier periods of productivity, the handicapped have not (p. 18 n. 30).

<sup>78</sup> This phrase is Bérubé’s, from a paper published after the book, entitled “Disability and the ‘Difference’ It Makes,” delivered at the Smithsonian National Museum conference on “Disability and the Practice of Public History,” May 1999.

### A.5 THE CENTRAL HUMAN CAPABILITIES

1. **Life.**  
Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. **Bodily Health.**  
Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. **Bodily Integrity.**  
Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. **Senses, Imagination, and Thought.**  
Being able to use the senses, to imagine, think, and reason—and to do these things in a “truly human” way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.
5. **Emotions.**  
Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)
6. **Practical Reason.**  
Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)

**7. Affiliation.**

**A.** Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)

**B.** Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.

**8. Other Species.**

Being able to live with concern for and in relation to animals, plants, and the world of nature.

**9. Play.**

Being able to laugh, to play, to enjoy recreational activities.

**10. Control over One's Environment.**

**A. Political.** Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.

**B. Material.** Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.



## appendix

# B

### Justice and Long-Term Care:

#### Need We Abandon Social Contract Theory?

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#### A Reply to Nussbaum

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Norman Daniels

### B.1 JUSTICE AND CARING FOR CERTAIN NEEDS

All of us are dependent on others in significant ways. We all face periods in our lives when we depend on others for basic forms of care, not only in childhood, but, with our increasing likelihood of living longer, during periods of chronic illness and during periods of frailty when we are old. Each of us faces a chance that we need, or someone we are responsible for needs, such care for extended periods as the result of illness, trauma, or birth defect. Dependency is part of the human condition.

What do we owe each other as members of society to insure that these needs are met? This is a basic question of justice, and adequate theories of justice should provide a plausible answer to it. I do not mean that all obligations to care for others are matters of justice, for justice obviously does not occupy the whole of our moral space. Some obligations of caring may be the result of special relations we have to our children, parents, or friends, or of professional roles we occupy. Even where some obligations to provide care derive from other ethical considerations, we may, as a matter of justice, owe each other various kinds of support that reduce the needs for such care or make delivering it more sustainable.

I want to suggest in this brief comment that at least one prominent theory in the social contract tradition, Rawls's theory of justice as fairness (Rawls, 1971) can be extended in a reasonable way so that it supports a plausible account of justice and long-term care. Indeed, I shall briefly describe one such extension, drawing on some of my earlier work (Daniels, 1985; Daniels, 1988). Of course, showing that the most sophisticated theory in a tradition can address a difficult problem does not defend the whole tradition, even if it does refute the claim that no theory in that tradition can address that problem. My goal, however, is not to defend the whole tradition but only one instance of it. Moreover, if I am

## ETHICAL CHOICES IN LONG-TERM CARE

right, there is an important convergence between Rawls and those, like Sen and Nussbaum, who focus on capabilities. The convergence is of greater practical importance than subtle philosophical disagreements that might remain. Knowing that different general views of justice converge on some more specific requirements of justice is additional support for their status as requirements.

### B.2 JUSTICE AS FAIRNESS: MEETING NEEDS AND PROTECTING CAPABILITIES WITHOUT BARGAINING

Before actually describing my extension of Rawls's theory to long-term care, I want to explain briefly why this particular contractarian theory can be so extended and why it is not subject to some of the objections Nussbaum has raised. A first point to emphasize is that Rawls's theory is not a theory about bargaining between haves and have-nots. In such bargaining theories, relative advantage shapes the rules contractors select as terms of cooperation. Rawls clearly rejects such an appeal to advantage as a possible basis for establishing fundamental principles of justice; accepting the influence of those inequalities in advantage means, in his view, that we have constructed a choice situation that is fair to all choosers. Rawls's phrase, "justice as fairness," means justice as procedural fairness: we accept as an account of justice what emerges from a contract that is fair to all parties, but accepting prior inequalities is not fair to all of them when we view them as free and equal citizens.

Rawls rejects the idea that the contract involves bargaining. Instead, moral claims about the fundamental equality of citizens, as well as their freedom, shape the design of his contract situation. He places contractors behind a veil of ignorance that blinds them to the specifics of their own situation. The result is that contractors must be impartial and cannot help but avoid judgments that might be biased in favor of people with their actual talents, skills, capabilities, or needs. So forceful is the restriction on knowledge of differences that any sense of bargaining away disagreements is eliminated. The contractors end up speaking with a single voice, a point some critics have said eliminates the whole idea of a contract. It would clearly be unfair criticism to lump Rawls with those squarely in the bargaining tradition.

A second fundamental feature of Rawls's contractarianism is that the choice of fair terms of social cooperation is aimed at meeting the needs of free and equal citizens, including their needs for long-term care. Behind the veil of ignorance he imposes, contractors represent people who not only have animal needs, including various dependencies, but also have values and goals—spiritual needs, if you will—that they hold to be fundamental. This development of the theory of the social contract thus models real people, not disembodied spirits, even if the representatives are blinded to some of their differences.

The fair terms of cooperation to which contractors agree take the form of

principles of justice. These principles tell us how to distribute various basic goods that meet our needs as free and equal citizens. In Rawls's theory, these goods are called the "primary social goods," and they include certain basic liberties, powers, opportunity, wealth and income, and the social bases of self-respect. Meeting these needs enables us to function as—that is, to have the capabilities of—free and equal citizens. Rawls's focus on enabling people to function as free and equal citizens is an important point of contact with Sen's view, for, arguably, he too focuses centrally on the capabilities needed by free and equal citizens (Anderson, 1999). Another point of contact is Rawls's argument that the parties to the social contract would choose principles that assure even those who are worst off that they will have the highest effective value or worth of liberty, insofar as it is achievable—a notion very close to Sen's talk about positive freedom.<sup>1</sup> Together these points of contact mean that fair terms of social cooperation—or principles of justice—for both Rawls and Sen involve assuring the capabilities of people necessary to function as free and equal citizens.

### B.3 SIMPLIFICATION, NOT PERMANENT OMISSION OR DEVALUATION

To make the initial contract problem more tractable, Rawls introduces a simplifying assumption about his contractors that invites the criticism that Amartya Sen and Martha Nussbaum make. He supposes that his contractors are fully functional over a normal lifespan. In effect, no one is ill, disabled, or dies prematurely. In effect, none of the special dependencies that are the target of long-term care need be addressed, at least for the initial framing of the social contract. If contractors can work out fair terms of social cooperation for this simple case, then perhaps the theory that results can be extended to cases that more closely resemble the real world. Obviously, if this initial simplifying assumption means the theory can never address problems of dependency or long-term care, or the protection of health more generally, then the theory is fatally flawed (as Nussbaum seems to suggest). To complicate the issue, Rawls himself does not attempt the extension in his early work, though he later appears to have endorsed the extension I have developed and shall describe.

Does his simplifying assumption mean that Rawls's social contract theory assigns a different value to people who are fully functional as compared to those who are ill or disabled? The way that his theory stages the task, and the division of labor that results, has been interpreted this way. Nevertheless, I believe that the theory does not at all yield this implication.

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<sup>1</sup> The worth or value of a liberty can be thought of as the capability to exercise it effectively. See Rawls, J (1971) *A Theory of Justice*. Cambridge, MA, Harvard University Press. p. 204; See also Rawls, J (1993) *Political Liberalism*. Cambridge MA, Harvard University Press, pp. 324-331. See also Daniels, N (2002) "Democratic Equality: Rawls's Complex Egalitarianism," in Freeman S (ed), *A Companion to Rawls*, Cambridge, Cambridge University Press (in press).

## ETHICAL CHOICES IN LONG-TERM CARE

Consider an analogy. When physicists or economists impose simplifying assumptions on a problem and develop laws to cover the “ideal” case, they do not mean that the ideal case is better than the non-ideal case, despite the term “ideal”; they only mean, or should mean, it is simpler. Once they can explain the simpler case, they can attempt to address more complex ones. If they cannot extend their theories to accommodate real-world conditions where the simplifications are not present, then their theories, whatever the simplicity and beauty, are of limited practical value and do not, after all, correspond to reality. Simplifying a problem does not devalue what is temporarily omitted.

Rawls’s simplification opens him to another criticism that Arrow (1973) raised from a welfarist perspective and Sen (1980) raised from his capabilities perspective: people with similar allotments of primary social goods may convert those goods into very different levels of welfare or capabilities. Arrow asked who really was worse off, the rich but sick person or the poor but well one, and he concluded that we should measure well-being in terms of welfare or satisfaction in order to answer this question since the index of primary social goods does not help us. Sen argued similarly that a person with a disability might need more resources than a person without disability to achieve a similar level of capability. Sen and also Nussbaum (2000) then argue that justice must focus on the space of capabilities (not welfare) and aim to give people adequate levels of capabilities.

Sen, it should be noted, is clear that considerations involved in developing an overall theory of justice, which must take concerns about liberty and efficiency into account, will force qualifications as to just what kinds and levels of capabilities we owe people assistance in achieving (Sen, 1992). Unlike Rawls, Sen has not attempted the systematic integration of these concerns about liberty, equality, and efficiency that are embodied in the contractarian approach that Rawls takes in justice as fairness. Instead, to focus attention on the selection of the correct “space” within which we should think about equality, Sen, like Rawls, simplifies the problem, ignoring the task of integration. Eventually, however, this simplification must be replaced by an effort to address the more complex task of integrating the various components of a theory of justice. In the real world, the development and fair distribution of capabilities is achieved by fairly distributing the goods that people need to sustain those capabilities. That is, resources of various kinds, including what Rawls calls the primary social goods, are the means—they are what we need and use—to affect the distribution of capabilities. Rawls was realistic when he focused on the means needed to alter the distribution of capabilities of free and equal citizens.

Similarly, Nussbaum’s account of basic human functions or capabilities, however attractive, must also address problems raised by competing claims on resources. Competing claims are complex, focusing not just on money, but on such diverse social resources as liberties, powers, opportunities, and

the social bases of self-respect. All of these types of resources are needed in order to develop and sustain capabilities. It may be possible to map nearly all of Nussbaum's basic functions onto the Rawlsian principles for distributing primary social goods that would allow for the fair distribution and development of capabilities, and Nussbaum hints at some steps in that direction (Nussbaum, 2000).

Even if we do that mapping, a theory of justice focused on capabilities must integrate competing claims in the way Sen and Rawls acknowledge (and Rawls actually does). Talk about capabilities is but one element of such a comprehensive theory. A focus on capabilities lets us recognize differences in capabilities and the need for care when capabilities are diminished in certain ways, but we also must address the problem posed by competing claims on the resources that are necessary to support capabilities.

#### B.4 EXTENDING JUSTICE AS FAIRNESS TO MEET HEALTH NEEDS

Rawls's strategy, as I noted, is to derive fair terms of social cooperation for fully functional contractors first, then to hope that we can extend the theory so that it addresses the complexity introduced by variations in functional status resulting from disease, trauma, and disability. Can the extension be made through reasonable modifications of the theory without introducing ad hoc distortions? I have elsewhere argued in detail that it can, and here I can only sketch this approach.

My suggestion has been to broaden the notion of opportunity that forms one of the primary social goods in Rawls's theory and to subsume considerations of health care under the scope of Rawls's principle guaranteeing fair equality of opportunity.<sup>2</sup> I construe health care broadly to include traditional intersectoral public health measures that reduce risks to health, as well as chronic and long-term care, including social support services needed when people cannot carry out basic tasks of daily living. The fundamental intuition is that significant pathology, whether physical or mental, and whether the result of disease, trauma, or genetic or developmental causes, reduces people's range of opportunity compared to what they would have were the pathology absent. If we believe it is important, as a matter of justice, to protect this range of

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<sup>2</sup> Like Rawls, I distinguish the protection of formal equality of opportunity from fair equality of opportunity. Removing social obstacles to people being judged by their talents and skills, such as racism, gender bias, or nepotism, by itself leaves people vulnerable to the misdevelopment or underdevelopment of capabilities as a result of legacies of inequality in the society. Fair equality of opportunity calls for robust measures to correct for the misdevelopment of talents and skills. But correcting for these socially induced sources of unfairness only makes it reasonable to extend the principle to cover variations in capability induced by pathology, whatever its source, especially once we note the difficulty of disentangling social from natural sources of that variation.

## ETHICAL CHOICES IN LONG-TERM CARE

opportunity, that is, to protect the range of functioning (i.e., the capabilities), people would have were they not affected by unfair social practices or pathology, then we have a principled framework for designing institutions that distribute various forms of care.

Since Rawlsian contractors would adopt a principle providing fair equality of opportunity, they have the basis for providing health care, including long-term care, to those who need it. Just what mix of public and private insurance or other institutions would be needed is a matter to be worked out. In the account I have developed, the theory implies that there ought to be universal coverage within a system that publicly or privately insures an array of needed services, adjusted to meet concerns about resource limits. I also note that Rawls's principles of justice each capture an important cluster of the main social determinants of health and its distribution in populations, so a full extension of his theory to health and health care is even more robust than can be indicated here (Daniels, Kennedy, Kawachi, 2000).

### B.5 SOME IMPLICATIONS AND QUALIFICATIONS

Three points about the resulting account are worth emphasizing. First, we all age, and as we do, the profile of our needs changes. Since societies also age, the profile of needs for the society will also change. A properly designed system must allocate resources over the lifespan in a way that does not devalue life at any stage of life, just as it must do so in a way that is fair to each birth cohort. This point does not mean we set up a "bottomless pit" problem. We are not committed, under resource limits, to meeting every need we encounter on pain of "devaluing" the lives of those whose needs we cannot reasonably meet. Rather, we must deliberate about how to meet competing needs over a lifespan in a reasonable way. This approach will in general mean taking resources from some points or stages in our lives and "saving" them for others in order to make our lives go as well as they can, given resource limits and the overall constraints of fairness between persons.

I develop this lifespan approach to justice between age groups in detail elsewhere (Daniels, 1988). In that work, I emphasize a point well known among those who work with caregivers: in meeting long-term care needs we must not only address the needs of those with health problems, but we should design systems to assure that those delivering care can do so in a sustainable way. Where this means family caregivers, usually women, the social supports must be there that assure such care does not burn out caregivers and is compatible with their continuing to pursue other goals in their lives. Fair terms of social cooperation lead us to protecting opportunity across the lifespan, and this means doing so for us in the various roles we may play as both care receivers and caregivers. Just how this social

obligation is to be reconciled with competing claims on resources is a problem that must be addressed, but the basis for the obligation is there.

Do these theoretical considerations permit us to arrive at clear, highly specific answers about how to ration, or allocate, resources under various conditions of scarcity? Well, not quite, but this admission leads me to the second point I want to emphasize. I do not think the Rawlsian theory, as I have extended it, leads us to such specific answers. Nor, I have suggested, does the capabilities approach that Sen or Nussbaum propose resolve these problems of allocation under resource constraints. In fact, general theories that purport to give answers to all these questions, such as utilitarianism, arguably offer unacceptable answers in many cases. Perhaps fine-grained principles can be developed, and philosophical research should continue to try to find them, but they are not likely to emerge and to produce consensus in the near or midterm future. I believe we must supplement principled accounts of justice with an account of fair process to provide those answers in a way that has legitimacy. I propose an account of such a fair process in priority and limit setting elsewhere (Daniels and Sabin, 2002).

My third point is that the opportunity language I use should be seen to converge with the capability approach. This convergence should not be surprising because my modification and broadening of Rawls's original concern about opportunity, which was focused primarily on opportunity to enter jobs or careers, was undertaken to solve the very same problem that Sen was concerned about (and roughly at the same time, the late 1970s). Both Sen and I were concerned about the insensitivity of the primary social goods viewed as a measure of well-being when faced with functional variations in people. My suggestion then (and now) is to save the primary social goods as a theoretical tool by expanding the concept of opportunity so that it is more broadly concerned with capabilities to function in the many different ways free and equal citizens need to function. Sen's solution then (and now) is to focus instead directly on the space of capabilities. I noted earlier that Nussbaum has hinted at some of the mapping that might be possible between the two notions.<sup>3</sup> I believe Rawls endorses the modification I have proposed of his view (Rawls, 1993), but whether or not he does, I have shown how his view might plausibly be extended not just to health care in general but also to long-term care specifically.

## B.6 A CONCLUDING REMARK ABOUT CONVERGENCE

For Rawls's theory to address health problems in the real world, his simplifying assumption must be removed. I have suggested that assumption can be

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<sup>3</sup> I would not, however, pursue a course of substituting a long list of other things, including health care, in lieu of the primary social goods. Long ago, others suggested that health care be made a primary social good; the extension I describe avoids that move by showing how to accommodate claims on health care within institutions that promote protection of opportunity. Nor do I think we should substitute a list of capabilities for the primary social goods.

## ETHICAL CHOICES IN LONG-TERM CARE

removed if we modify Rawls's narrow notion of opportunity and at the same time notice the important way in which impairments of health and limits on functioning constitute reductions in opportunity that are matters of justice. If I am right, then one prominent social contract theory can address problems of long-term care. We need not, then, conclude that the contract approach to establishing fair terms of social cooperation makes it difficult or impossible to address those problems, though we may have to be generous in how we modify and extend the theory.

The same challenge is faced, in my view, by other approaches to talking about equality and justice, such as Sen's or Nussbaum's versions of the capabilities approach, which use somewhat different conceptual and moral apparatus. Only when they are extended to incorporate concerns about how to balance liberty, efficiency, and equality under reasonable resource constraints, will they begin to tell us what justice requires in the way of long-term care.

My hypothesis, given what I think is a convergence on a similar "space" within which justice is addressed, is that plausible versions of Sen's or Nussbaum's views will resemble my extension of Rawls's theory. If there is such convergence, then I think we will be in the pleasant situation of having several routes to a similar, just goal. Here I prefer to work out how much convergence there is rather than emphasize differences, which may prove to be technical and minor.

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## appendix

# C

### Can Contractualism Justify State-Supported Long-Term Care Policies? Or, I'd Rather Be Some Mother's Child

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### A Reply to Nussbaum and Daniels

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Eva Feder Kittay

Contractual theories of justice typically posit parties to the social contract who have capacities of fully functioning adults. In *Love's Labor*, I argue that these theories do not consider the fact of or the social consequences of “inevitable human dependency”—that is, the dependences of protracted childhood, frail old age, illness, and severe disability. In the book I undertake to demonstrate this point with respect to the work of John Rawls. Furthermore, I argue that the implications of such omissions are felt not only by dependents, but also by those who do the work of caring for dependents, a form of caregiving I call “dependency work.” I maintain that including the needs and interests of the inevitably dependent and their caregivers should be a criterion of adequacy for any theory of justice. Only theories that are adequate in this way will provide good guidance for formulating just policies regarding long-term care. Martha Nussbaum makes a still stronger claim, insisting that contractual theories are ill-suited to considering the needs of inevitably dependent persons and so will be unhelpful in justifying and constructing policies providing for long-term care.

Nussbaum proposes an alternative view that puts the development of capabilities at the center of a theory of justice. Her theory does not begin with an abstraction or idealization of the person as a fully functioning adult but presumes that we are born helpless, become ill, and grow too frail to carry on as we did before. It also presumes that not all among us are fully able-bodied and in full possession of cognitive capacities; rather, that among us are some who have impairments of various sorts.

Rawls understands that his is an idealization intended only to provide basic concepts, which can then be extended to meet other needs and requirements. We have to ask whether a theory that is constructed on the assumption that

## ETHICAL CHOICES IN LONG-TERM CARE

we are all fully functioning, that dependency and need for care constitute an exceptional state—rather than a normal part of a human life—will be able to put the concerns of individuals who are not modeled in the theory on par with other matters of justice.

I believe that Nussbaum and I share the view that starting with this idealization of the person obscures a fundamental role of all societies. That function is to provide the circumstances under which humans can be cared for and thrive, given their differing degrees of frailty and vulnerability. Contractual theories, however, require just social and political organization to establish fair terms of social cooperation in which the benefits and burdens of social cooperation are fairly shared and fairly distributed. Our ability to participate in a system of social cooperation, and to assume our fair share of the burdens of social cooperation, is key to our participation as equals in a society ordered according to such principles of justice. Furthermore, for a society to be just on this account, it must not be ordered in such a way that some receive the benefits of social cooperation while obstacles are placed in the path of others. Instead, all should be provided with a fair equality of opportunity to compete for the benefits of social cooperation. But these two conditions can be problematic both for persons who are dependent on others for essential care and for those who do the caregiving. Most obviously, if a person is dependent on another for the most basic care, her ability to participate in the competition for social goods is importantly limited.

As I will show shortly, it is to this consideration that Normal Daniels's emendation of Rawls is most pertinent. But this is not the only difficulty. Dependent persons may also not be fully capable of sharing the burdens of social cooperation—in fact they are dependent on others just to care for themselves. With that care, and with certain modifications in the physical environment, they may in fact be capable of substantially contributing materially to society. But they may not be—or their contributions may be very limited. If moral considerability depends on taking on a share of the burdens of social cooperation, those who cannot do so, or can do so only to a very limited extent, are excluded from the principles of justice. And when the distribution of social goods is conceived to be just whenever conditions of fair equality of opportunity apply, those who are caregivers to dependent persons are also frequently shortchanged. For as they turn their attention to the well-being of the person in their charge, addressing his or her needs even to the exclusion of their own, using their own voice to articulate the interests of another, their own ability to enter into the competition for goods is severely curtailed. As a consequence, dependency workers, who surely can be said to share the burdens of social cooperation, may still fare rather poorly under a contractual model of justice.

Nussbaum points to Scanlon's suggestion that the most congenial way of taking interests of dependents into account is through a trusteeship exercised by the fully functioning on behalf of those who are dependent. She argues that this

slights the dignity of persons in need of care, for it makes it appear that they are worthy of political consideration only to the extent that there are independent individuals who can serve as trustees. Furthermore, it suggests that the animal needs of human animals are not in themselves worthy of attention—that is, that the mere fact that persons are in need as a consequence of inevitable human dependencies ought to suffice as a ground for attending to these needs. To these arguments I would add that the status of the trustee and his or her interests is also problematic, for the trustee, like the dependent, is an actual person with real interests and needs. If the trustee's interests get submerged as she speaks on behalf of her charge, she is not treated on par with other citizens. If she allows her own voice and her own interests to predominate, then the dependent is not recognized as an equal. The notion of a trusteeship does not succeed in bringing both the trustee and the charge into the fold of a contractual model of justice.

Norman Daniels disputes the contention that a robust contractual theory of justice such as Rawls's cannot incorporate the concerns of dependents in need of long-term care. He maintains that it is unnecessary for these concerns to enter at the most basic level of the theory if they can be incorporated at a later stage. He proposes that by considering health-related needs—including those of long-term care—to be part of the primary good of fair equality of opportunity, we have all the theoretical tools we need to include dependents and caregivers alike within the scheme of Rawlsian contractual justice. Nussbaum's move to a capability approach, Daniels contends, is not in conflict with the right sort of contractarian theory. On the contrary, the capabilities approach, he suggests, is only a small modification of the fair opportunities approach that he has pursued and that Rawls himself appears to have accepted as a friendly emendation. Does Daniels thereby rescue Rawlsian contractualism for long-term-care concerns?

To try to answer this question let us think about the way in which Rawls himself deals with another sort of problem, the matter of intergenerational justice. Rawls was concerned that when the parties to the original position determine the principles of justice they choose principles that allow citizens to exploit, deplete, or spoil present resources to enhance prospects of those who are current members of their society, leaving little for future generations. To this end Rawls saw fit to include, in the very foundation of the theory, not at a later state of development, a "just savings principle." The just savings principle stipulates that just as previous generations had the obligation not to exhaust resources for the current generation, our generation has the obligation to reciprocate by not depleting resources for those who come after us. To assure that the just savings principle be respected, Rawls posited that representatives in the Original Position not only were ignorant of their station in life, but also did not know to what generation they belonged. He reasoned that by acting out of rational self-interest, the parties would then choose principles in conformity with the just savings principle.

## ETHICAL CHOICES IN LONG-TERM CARE

We could argue analogically that parties representing those who are at a period in their lives when they are fully functioning might well choose principles disadvantageous to those who are not fully functioning. Perhaps we could then posit something analogous to the Just Savings Principle, ensuring that just as those who are fully functioning received resources *and care* that enabled them to become fully functioning adults, so they need to reciprocate by ensuring dependents will receive the resources and care they require to shed their dependence. This would be a start for a contractual theory that takes the needs of dependents and caregivers into consideration, and it may well be what Daniels achieves by expanding the good of opportunity to include health-related needs. For we all require health-related goods to have the opportunity to become fully functioning adults who can join in a fair system of social cooperation. Without adequate health care, whether it be acute care or long-term care, we cannot function as fully cooperating members of a just society and hence, health-related needs are among the goods encompassed by the primary good of fair equality of opportunity.

But what, one might ask, of those who will never become (or never were) fully functioning adults capable of assuming the burdens of social cooperation and competing for the goods of a well-ordered society? What about the babe doomed to die before she reaches maturity because AIDS was transmitted to her at birth? What about the young adult with traumatic brain injury resulting from an automobile accident or a wartime strike who never again will be able to fulfill his duties as an adult citizen yet might live well into old age? What about the severely or profoundly cognitively impaired individual who cannot speak or care for her most basic needs, much less participate as a citizen and worker? Will tending to the needs of these individuals be fully justified by considering health-related needs as required for their fair equality of opportunity? The answer may depend on the answer to another question: Fair equality of opportunity for what?

Daniels writes that the opportunity language he uses is a modification of Rawls's original focus on the opportunity to enter jobs or careers, and that this sense of opportunity converges with that of Sen. This convergence, he tells us, is unsurprising because he, like Sen, was "concerned about the insensitivity of the primary social goods, as a measure of well-being, to address functional variations in people." Daniels writes that he wanted to "save the primary social goods as a theoretical tool by expanding the concept of opportunity so that it is more broadly concerned with capabilities to function in the many different ways free and equal citizens need to function."

But does Daniels's modification help address that insensitivity and thus cancel out the shortcoming that arises out of the idealization? If the opportunity with which we are concerned is the opportunity to live as full and rich a life as we can, to flourish as fully as we are able, then it may make little difference whether we speak of capabilities or opportunities. But capabilities or opportunities only

address half of what is encapsulated in the notion of social cooperation. The social contract, even in Rawls's most capacious view, is entered into to establish fair terms of social cooperation, that is, the principles that determine how we distribute the benefits and burdens of social cooperation. Primary goods such as wealth and opportunity to achieve wealth and occupy professions and offices are among the benefits of social cooperation—but what about the fair terms of cooperation with regard to the burdens?

There is a presumption in social contract theories such as Rawls's that those who are fully functioning will assume those burdens not only because they are presumed to have a sense of justice, but also because they must compete for the goods that come about as benefits of social cooperation. The competition for these goods, it is assumed, is in itself productive of benefits. It is, after all, the very competition for the goods of social cooperation that is productive of wealth and other resources, which in turn become available for distribution. That is why fair equality of opportunity is so important. It provides people with a fair chance to compete for those goods and in the process contribute to the store of goods. I suggest that it is not incidental to the contractual project that Rawls emphasizes the opportunity for education, jobs, and offices. The sort of health-related issues Daniels includes will help to make many more individuals productive for a greater portion of their lives and will offer people the incentive of knowing that when their productive lives are over, they will continue to be provided for. To this extent, expanding the idea of opportunity to cover health-related needs contributes to the contractual conception at the heart of Rawlsian theory.

But once we consider populations who may never be productive, the rationale for meeting their needs is less clear on a contractual model. Perhaps the group who cannot be productive—at least in the terms that we ordinarily understand productivity: contributing to the material benefits of a society—is in fact quite small. Even those with significant disabilities can, as the disability community has argued, be productive if the environment in which they function is made more accessible. Perhaps those excluded includes only a small number of profoundly cognitively impaired individuals, for example, and children who we know in advance will die well before they enter the productive stage of their lives. In that case, does their omission from a contractual theory of justice warrant discarding an entire set of theories that have a long and distinguished pedigree?

Perhaps not. But perhaps there is a real danger in excluding even a small population. For if we say that there are some who just aren't capable of sharing the burdens of social cooperation, and who just cannot be productive and who therefore are not subject to the principles of justice, might we not ask about the *degree* of productivity of others who may have very significant and long-lasting needs for care, needs that incur costs that are in excess—to a notable degree—of their contribution to the benefits of social cooperation? And when we start to walk down that path, may we not at some point find ourselves

## ETHICAL CHOICES IN LONG-TERM CARE

back at the giving of full equality only to the full-functioning adult? But now it is not because we are considering society as comprised of fully functioning adults as a mere idealization for the sake of theory simplification. Instead the idea becomes a desideratum that bestows a badge of merit to the fully functioning adult and denies it to those who are dependent on others for care. Now, it would seem that meeting the needs of these meritorious citizens becomes the priority and those who are in need of care are served only the leftovers, the scraps, charitably or not so charitably meted out to those who fall behind in the competition for the goods of social cooperation. "Receiving leftovers" furthermore is metaphor for what is made available materially and for the attenuation of political voice of those who are or become dependents.

Daniels is certainly correct in maintaining that "Rawls's theory is not a theory about bargaining between haves and have-nots." Yet when we consider what the primary good of opportunity is the opportunity for, and how the notion of opportunity is situated in the contractual understanding of a well-ordered society as one based on fair terms of social cooperation, we see that even Rawls's contractualism is at heart a bargaining for mutual advantage in which only those who are both equally empowered and equally situated reap the major benefits. But those who are dependents are not equally empowered, and those whose energies are directed at caring for and protecting the interests of dependents are not equally situated. It is not clear that any modification of the theory will redress this difficulty, because the difficulty goes to the heart of contractualism.

Rather than conceive of a just society as first and foremost one based on fair terms of social cooperation, Nussbaum is suggesting that we understand a just social order as one that assures the dignity of each of its members by tending to the inherent needs of humans beings, by ensuring that each individual is given the equal possibility of the free functioning of their capabilities. Bypassing the contractual step means bypassing assumptions of worth based on normal functioning and productivity.

Nussbaum and I are thus far in agreement. But Nussbaum believes that I go further, rejecting all liberal conceptions and relinquishing the ideals of freedom and independence for "a conception of the state that makes it the parental supporter of its 'children's' needs." This is a view she attributes to me based on my suggestion that we substitute for the liberal conception of equality the idea of equality inherent in the understanding that "we are all some mother's child." I put forward this proposal as a better way to capture our inherent equality in the face of inevitable human dependency. But my view is not that the state serve as a metaphorical parent, nor that citizens are merely childlike in their needs and interests.

While this is not the place to set the record straight on all accounts, I wish only to clarify my position to the extent that it bears on questions raised here. When I remind us that we are all some mother's child, and that we use that phrase to recall to ourselves our common humanity and equality, I wish to invoke the care required for each of us to survive and thrive. Furthermore, the phrase recalls there is a someone who provided that care, a someone whom we fail to honor and respect when we fail to continue to care for one another *and* to care for the one who provides us with care. To fail to honor that relationship is to fail to honor the founding relationship between people. This is not to say that the state ought to treat each of us as a *child*, but as *someone's cherished person*. Moreover, a mother, no less than the state, must treat a child in a way appropriate to her needs and her situation. A mother who treats her adult child as an infant, as someone who cannot make decisions autonomously, is not functioning as a very good mother. A state that patronizes its citizenry, makes decisions for individuals that they ought to be making for themselves or does not give persons the possibility to exercise agency as fully as possible, does not, in my view, treat its citizens as "some mother's child."

That we are some mother's, I take it, implies that a caring society must not only provide long-term care for its citizenry, it must also make its environment, its laws, and its attitudes conducive to allowing individuals who may have impairments, chronic illnesses, or diminished capacities because of illness or old age function as fully as they can function for as long as they can do so. And this is not because such policies will make people productive and able to assume the burdens of social cooperation, but because the exercise of agency is an important element of flourishing—and what more could a mother want? I do not intend to disparage liberal ideals but only the pernicious notion that we are independent in some absolute sense, that dependency is to be avoided at all costs. Dependency is not an evil, it is a fact of human existence. As long as we can appreciate this and hold it in view, as long as we create societies that provide for the needs of long-term dependency and care, these insights are compatible with the importance of providing people space to develop their individuality, their autonomy, and their independent agency.



A consensus appears to be emerging that all citizens should be able to secure equitable access to health care, including long-term care. But if this is a broad consensus, it is also a thin one. There is no agreement on the political solutions necessary to improve access, on the role government should play in these solutions, or on methods of financing. Moreover, given the fragility of the support for equitable access, developing appropriate public policies that allow implementation remains a challenge.

As the discussions move forward, some of the unique features of the African context should be kept in mind. Though many of the ethical principles relevant to long-term care are universal, certain factors are heavily influenced by cultural norms and economic realities. In particular, the following should be noted:

- Long-term care should be provided in a way that promotes the African culture of solidarity and respects the sanctity of life.
- The principle of autonomy may be moderated by considerations of family and community. The communal nature of African society dictates that individuals do not belong to themselves or their families, but rather to the society. As such, the responsibility for, and the consequences of, decisions may be borne communally. The communal emphasis also complicates issues of confidentiality.
- Beyond the intricate reciprocal arrangements that exist within many African societies, virtues of charity and moral ideals are inadequate to the task of meeting many health care needs. The older models of voluntary assistance have gradually given way to a controversial model of an enforceable right to health care based on justice.
- Productivity may become a justification for resource allocation. In the harsh African context, access to scarce services may be linked to the survival of a people. From this perspective, consideration may be given to the whole community, rather than to its individual members.

## ETHICAL CHOICES IN LONG-TERM CARE

- Though women are often the most economically productive population group, the distribution of resources may not favor them as they are often subject to discrimination and may be considered “replaceable.”
- The welfare of other family members must be considered when decisions are made about resources to be invested and services to be provided. The impact of caregiving on the extended family and the social network may be cushioned by its reciprocal nature, but this cushioning is usually not gender-balanced.
- Spiritual and emotional support—encompassing visits, fellowship, prayer, and sharing—is as much a part of caregiving in the African context as physical support and can be done by informal caregivers.
- Caregivers must be careful not to exploit traditional generosity while providing home-based care. While it may be appropriate to accept food that is offered, accepting gifts of livestock and other core resources can impoverish a household.

## **appendix**

# **E**

## **List of PARTICIPANTS ETHICS and LONG-TERM CARE CONSULTATION**

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## ETHICAL CHOICES IN LONG-TERM CARE

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Existing systems of long-term care for people with chronic illnesses and disabilities are not enough to meet the growing demand. Though unpaid family members will continue to play a central role in providing care, states must ensure that resources are available to address growing needs and that those resources are distributed efficiently and equitably.

A society invites a dialogue about how best to structure the ethical framework within which equitable, fair, rational, and transparent decisions about long-term care can be made when it asks: What long-term care needs exist? What resources are available to provide them? What does justice require? The answers point the way towards systems that are responsible, accessible, efficient, and accountable, and that address the universe of human needs with dignity and respect.

The primary goal of this report is to reflect on the moral basis of long-term care and to identify some of the issues that need to be considered as those systems are designed.

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