A Missed Opportunity:  
The President’s Council on Bioethics Report on  
Ethical Caregiving  

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The rapidly expanding population of elderly persons who require care is raising critical  
questions for families and for public policy. What is required of us ethically, as  
individuals, family units, and as a society? How can we best organize our resources to  
support those in need of care and those who provide it? Complicating matters of course  
is the fact that at the same time the numbers of those needing care is on the rise, family  
size is shrinking, women—the traditional givers of care for family members—have  
entered the paid workforce en masse, and there is mounting pressure to contain health  
care costs.

The ostensible objective of the report, Taking Care: Ethical Caregiving in Our  
Aging Society, issued in September 2005 by the President’s Council on Bioethics  
(PCB)—then under the leadership of Leon R. Kass—is to grapple with the many pressing  
ethical issues presented by this state of affairs. In his letter to the President, the former  
chairman writes: “[The report] seeks to gain attention for a burgeoning social problem  
and to offer ethical guidance regarding the care of our elders who can no longer care for  
themselves” (ix).
Yet, as one reads on, it becomes clear that the PCB has construed ethical issues in caregiving for society, families, and the aged, in a quite constrictive way: “how ethical caregivers should decide and act” (204), or, “when, how, and why to intervene or not intervene with the medical art” (116) at the end of life in clinical and other health care settings, primarily for one subset of patients—those suffering from Alzheimer’s disease and other forms of dementia. It takes just three short paragraphs into the letter to President Bush to uncover the main mission of Taking Care: to offer an indictment of assisted suicide and active euthanasia. The timing of the report’s release is telling in this regard: It was issued on September 28, 2005, as the United States (U.S.) Supreme Court was preparing to hear arguments in the case of Gonzalez v. Oregon. Readers might also wonder what, if anything, the emphasis upon the formerly competent might have to do with the case of Theresa Marie Schiavo, which at the time was still fresh in the minds of many.

To claim that the Council’s focus is unduly narrow is not to suggest that the issues the report addresses are unimportant. Yet the report covers already well-trodden ground concerning euthanasia and assisted suicide, advance directives and proxies, and medical decision making for the formerly or never competent. It therefore fails to seize the opportunity to use its considerable resources and expertise to contribute to the discourse—and eventually the formation of more ethical public policy—on the many other issues concerning caregiving that have received scant attention from the bioethics community in the U.S. Anyone who has experience with and/or interests in long-term care will find little here that is new, compelling or helpful. And those who have come to believe that the PCB under Kass’ leadership aimed at using this public body to advance
an identifiable—indeed conservative—political agenda will find still more supporting
evidence (Charo, forthcoming).

As the main body of the report begins, it seems promising. Its opening chapter,
“Dilemmas of an Aging Society,” presents data on impending changes to the age
structure of the U.S. population, describes the changing course of illness and death—
attributable mostly to a century of progress in public health and medicine—and then turns
to a problem, or really a set of problems, that has yet to capture the attention of
mainstream bioethics: the scarcity of caregivers and the implications of this for the
quality of care given to the elderly and dependent. To its credit, the Council notes the
disproportionate burden borne by women—an increasing number of whom are now
working in the paid labor force yet are still most likely to take on the role of caregiver in
families, although doing so puts them in considerable social, economic, and health
jeopardy (16-17).

Yet it does not take long for the narrowly constructed report to ratify the ethically
troublesome status quo. Given the way the report organizes the discussion, it would seem
that at least some share of the responsibility for the looming “crisis” in caregiving for the
elderly and dependent is women’s, as they are more likely in contemporary society to
hold jobs and to be divorced. “Such working family caregivers” the report remarks,
“often have to give up years of income, or accept less pay or advancement, in order to
care for their elderly family members for extended periods. Caring for elderly relatives
[moreover] will often come into competition with raising a family of one’s own . . .” (18).
This seems fairly benign until one delves deeper. “[F]idelity has surely been tested in the
modern world—not only between spouses but between parents and children . . .” (96).
The growing need for caregiving, the Council suggests, “will test our character and self-understanding, requiring us to set aside self-interest in order to care for those who can no longer provide for themselves” (20). We will:

- have to make hard choices between competing goods . . . [and] . . . avoid two crises: . . . the danger that some old people will be abandoned . . . and the complete transformation of caregiving into labor, creating a situation where people’s basic physical needs are efficiently provided for by “workers,” but their deeper human and spiritual needs are largely ignored, because those with the closest ties are unable or unwilling to be with them (47-48).

In the section entitled “Defining the Subject” they ask, “What in the broadest sense do we mean by “the ethics of caregiving”? (100). Ethical caregiving here calls, above all, for the virtues of justice and fidelity on the part of family members (101).

But where is the discussion of the social and economic reforms that might support caregivers and the dependent elderly? Where is the consideration of workplace reforms, including, for example, meaningful family leave policies? Where is an exploration of strategies to support—financially and otherwise—those who would remain in the home to give care full time? What makes good care possible, most fundamentally, on the view presented here, is “manifesting and acquiring the caring character so indispensable to the task . . . “ (149).

To be fair, the Council does ask: “What constitutes good care, what makes it possible, and how can we become or support good caregivers?” (95). They note here the necessity of understanding “the many social, economic, and institutional factors that
dictate whether good care is possible” given that “[f]amily caregivers cannot care well in isolation” (96). They need support such as “respite care programs . . . ; federal laws that protect caregivers who leave work temporarily . . . ; state programs that support a flexible menu of long-term care options . . . [and] to honor and reward caregiving, rather than seeing it as unskilled or undignified labor” (96-97).

Yet that is the whole of the Council’s contribution on these matters, arguably the most integral issues concerning ethics and caregiving. Feminist and other scholars working in philosophy, economic and health policy have devoted considerable attention to these issues (Kittay, 1999; Tronto, 1994). The Council, however, does not draw upon their innovative and thoughtful work.

When it comes its discussion of those who receive pay for the crucial work of caregiving, the “workers” referred to above—nurses and more importantly, nurse assistants and home care aides—the Council again seems poised to make great strides but falls short. The report refers to the challenges posed by the “strenuousness of the work . . . compensation barely above minimum wage . . . the lack of health insurance and other benefits, and hindrances to immigration” (18). But again, they leave it at that, thus failing to use the report as an opportunity to present and further the scholarship on the re-evaluation of not just unpaid but also paid caregiving (Kittay, 1999), the plight of immigrants working as caregivers in affluent countries like the U.S. (Neysmith and Aronson, 1997; Chang, 2000; Hondagneu-Sotelo, 2001), and the implications for global justice of the migration of workers—especially women—seeking nursing jobs in these countries (Chaguturu and Vallabhaneni, 2005; WHO, 2002). While these are among the most crucial ethical issues for consideration and commentary on caregiving, U.S.
bioethics on the whole has shown no interest. Despite their prominence and power, the PCB helps to maintain our collective myopia.

So far we have considered what the Council has to say (and does not have to say) about those who do the work of caregiving, but what about those in need of care, that is, the aging? Again, strikingly, the report’s discussion is couched in the language of virtue ethics. Indeed, not only does aging call for virtue on the part of family members as noted above, it “requires [in an elderly person] the cultivation of character necessary to endure one’s own decline” (20). The ideal “traits of character” include courage, simplicity, wisdom, humor, gratitude and acceptance (23). William F. May, quoted here, suggests that these “grow only through resolution, struggle, perhaps prayer, and perseverance” (22).

So, despite its mention of some of the social, economic and institutional issues involved, the structure and content of the discussion make it hard to avoid the sense that the PBC understands ethical caregiving as fundamentally a matter of cultivating virtue among the elderly and their family caregivers, and of decision making at the end of life.

At the heart of the report, in the section “The Ethics of Caregiving,” the Council observes that most discussions about aging, dying and caregiving have centered on “end of life issues” and poignantly adds:

We must also remember that caregiving involves not only those moments when life comes to a point, or only those decisions regarding the use of medical interventions to sustain or end life. Caregiving, especially for persons with debilitating illnesses . . . involves much more the daily
activities of being there for the person in need: protecting them from harm, managing their affairs, comforting them in dark times . . . (119)

This would seem to suggest that they see the need to expand the discussion about the ethics of caregiving beyond matters concerning clinical care, and to attend to the social and institutional context surrounding those who provide care, particularly family members (i.e. mostly women). But they go from here into an extended discussion about the “moral guidelines and moral boundaries that should guide caregivers” in making decisions about the elderly at the end of life (130).

Ethical caregiving is not, then, it seems, a matter that calls for truly transformed social policy. It is not about undertaking the complex work of responding to pervasive ageism in society and in the delivery of health care (Alliance for Aging, 2003; Nelson, 2002), of challenging gender roles that assign caregiving tasks to women (Bubeck, 2002; Kittay, 1999) and persistent discrimination in the labor market that creates a profound gap in earnings (Rose and Hartmann, 2004), a gap that contributes to the unequal division of (unpaid) caregiving labor. It is not about considering how to re-value—in terms of respect as well as financial support—the work of caregiving, professional and familial (Daly, 2001; Folbre, 2001), or how medical practice, health care institutions, and the workplace might be transformed to allow for increased support for family caregivers (Blustein, 2004; Ronch, 2004; Levine, 1999; Nelson, 2002; Kittay 1999), or improved conditions for those, like nurse assistants, who are paid to care in institutional settings like long-term care facilities (Nursing Home Community Coalition of New York, 2003). It most certainly is not about considering the place of the United States in the international context of caregiving, where global economic arrangements contribute to an
unjust distribution of resources that favors affluent countries and perpetuates inequalities for developing ones (Schutte, 2002; WHO, 2002; Farmer, Furin, and Katz, 2004; Chaguturu and Vallabhaneni, 2005).

To take one example of the marked contrast between the way some scholars see the issues at hand, and the way the PCB regards them, consider the matter of our shared vulnerability. For theorist Eva Feder Kittay (1999) as well as the Council, our shared need for care is part of what accounts for equality among persons and what serves as the basis of community. Whereas Kittay uses this “ethic of equality” to argue for new ways of thinking about the terms of social organization and cooperation, and for transforming a variety of social norms and institutional structures for the purpose of supporting the dependent and those who care for them, the Council takes it as a launching pad for arguing against assisted suicide and active euthanasia, for urging caregivers to resist temptations (spuriously attributed to them) to deny “respect and care” to those whose capacities are diminished:

We should recognize that caring for another entails certain obligations, including . . . the obligation not to seize an occasion for the person’s death, and the obligation never to allow our own desire for relief from caregiving to corrupt our sense of what it means to benefit the (even minimal) life the person still has (112).

Not only does the report fail to offer guidance on a range of ethical issues in caregiving for the elderly so far ignored by U.S. bioethics, it casts aspersions upon those who are engaged in the work of providing care—so often a labor of love—with the most minimal of social supports.
There are undoubtedly some bright spots in the report. For example, the Council’s discussion of ethics and caregiving acknowledges our embeddedness and interdependence as human beings, and thereby moves away from the tendency of Western moral philosophy to see persons as fundamentally detached and self-sufficient, a tendency that has shaped much scholarship in U.S. bioethics. They also importantly note that the women are the ones who bear the disproportionate burden of caregiving work. In these ways, the report draws upon contributions made by scholars on “the ethics of care” (though it does not name them and thus give them their due). Still, the Council falls prey to the problem often cited with this line of thought, namely that it focuses on valuing what has been and still is “women’s work” and the moral capacities that go along with it, yet serves to give inadequate attention to concerns of social justice.

They should also be applauded for highlighting the idea that aging should not be seen as mainly a medical condition but rather, understood as having the potential to afford us a set of rich psychological, existential, and social experiences (21, 48). The Council should also be praised for noting (albeit in passing) that this is most likely to occur against a backdrop of financial security and access to basic health care for all (26).

Finally, the Council issues a call for a Presidential Commission on Aging, Dementia, and Long-Term Care. Some might say more than one commission is in order here, and not all would sanction it under this presidential administration, but nevertheless, they underscore the need for continuing the conversation.

Despite these virtues, however, the overall tenor of the report is that of privatizing what is arguably a matter for public policy. Care of the elderly requires coordination of existing health and social services, improved and extended health and social services,
public funding, and above all, a widespread belief that the care of the elderly and
dependent is everyone’s business. Because the terms of this report are so narrowly
circumscribed, the Council has gotten us off to a disappointing start.

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