Love’s Labor Revisited

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Love’s Labor explores the relations that dependency work fosters between women and between men and women, and argues that dependency is not exceptional but integral to human life. The commentaries point to more facets of dependency such as the importance (and limitation) of personal narrative in philosophizing dependency (Ruddick); the role of spirituality that Gottlieb addresses with regard to his disabled daughter; and the application of the theory to the situation of elderly women (Tong).

Love’s Labor was launched by a rather modest ambition: to respond to a request to write a paper addressing the elusiveness of women’s quest for equality. I concluded that neither critiques of the way in which feminists had pursued equality nor reservations about the concept of equality itself were fully sufficient to explain the extent to which equality has eluded us. Few theorists had acknowledged that women’s traditional role in caring for dependents continued to be a major obstacle to equality. When they did, the issue was often treated as just one more way in which women either have permitted themselves to fall into the trap of altruistic behavior or have not yet fought hard enough to extricate themselves from roles imposed by domineering men.

Most women who have children have primary responsibility for dependency care for a few years of their lives—their children grow up and they are freed up. At that point, it is hard to remember the extent to which dependency care overtakes one’s life. It may also be hard to reflect on why so many women do not simply refuse the role of caregiver when a broader set of options and opportunities becomes legally available and socially acceptable. Having lived with a profoundly dependent person for virtually all of my adult life, I have had more years than most to reflect on the bonds, moral obligations, and dilemmas that responsibilities for dependent persons impose—an experience that Gottlieb and his partner share with me and of which he spoke so sensitively.
Someone must care for dependents. If men do not take up the role, women will not simply abandon it. Feminists may persuade women that liberation and equality demands refusing nonreciprocated affective labor directed at fully functioning adults. Women might even be convinced to lower their housekeeping standards to avoid being exploited by cohabitating adults and older children. But no feminist movement would, could, or should urge women to neglect the needs of their dependent children, or those of their disabled, ill, or ailing family members and friends. Most women do not intentionally neglect such responsibilities and tend to do so only under conditions of extreme poverty, serious illness or other duress. Women, in their roles as dependency workers, will not “strike” (so to speak) on the hope that men might thereby be induced take on the labor traditionally assigned to women. Women can and do delegate these responsibilities to family members or friends and to persons they employ, usually other women. Because dependency labor has never occupied a clear place in our economic order and paid labor competes with a vast unpaid workforce, dependency work tends to be poorly paid. Yet even at the depressed wages of paid dependency work, for many, the cost of this labor seems too high, especially as it is expected to be free when performed by female family members. A married woman who is supported by her spouse calculates whether her salary is sufficient to make it worth her while to employ someone else to do the work. The women most able to enter equally into the world of men are those who have been free of dependency responsibilities or who can afford to delegate dependency work to others. Because women cannot coerce the men in their lives into a full and equal sharing of dependency responsibilities, too often they need the exploitative labor of other women to achieve an “equality” measured by the norm of fully functioning white men. (Of course, as one of the respondents illustrates, a number of men do not need to be coerced, and do at least their fair share of dependency work, but they remain the lauded exception, and not the rule.)

This line of thought had led me to the dependency critique that Rosemary Tong has so precisely recounted. I saw that this critique of equality intersected with but went beyond each of the other critiques I identified. The more I researched, the more I became overwhelmed with how much territory the issues of dependency traversed: the vast literature on equality, political theories of liberalism, empirical and theoretical work on welfare, the structure and organization of work, the economics of dependency care, a host of issues in medical ethics, and—what was closest to home—disability. I could only touch on some of these in the one volume. What strikes me now is how much I failed to see as related to dependency concerns.

I failed, for example, to realize fully how intertwined questions of dependency were with a feature of the work that Sara Ruddick emphasizes, namely, the use of personal narrative in formulating philosophical theory. The ques-
tions she raises at the end of her paper also show how complicated is the relation between the personal and the theoretical. The early proposals and outlines of the book did not include a discussion of disability, much less an account of my relation to my daughter, Sesha, or her caregiver. It had not occurred to me to include personal material in a book whose centerpiece was a detailed theoretical analysis of John Rawls's theory of justice. I had never discussed my experience with my daughter in my philosophical work. And while I had wanted to write something someday, I was not sure it would contribute directly to a philosophical question. The account came into being as a consequence of Sally Ruddick's invitation to contribute to her edited volume *Mother Trouble* (Hanisberg and Ruddick 1999). I approached the project with trepidation, but when I sat down to write, the essay simply emerged—out poured nearly thirty years of reflection. The chapter (Kittay 1999) in *Mother Trouble* became a part of the book when I gleaned how intimately my experience of mothering Sesha was connected to my theoretical preoccupations regarding equality. I find that I cannot but help discussing a host of theoretical issues concerning disability, justice, and care without foregrounding my experience with Sesha, yet I am still trying to understand why discussing this singular case is so helpful. I am grateful to Sally (this volume) for introducing Hannah Arendt's concept of "representative significance," which is useful for articulating my project.

We are well advised to consider, as Roger Gottlieb asks us to do, why it has taken so long to think deeply about disability and caregiving. He suggests that it is because so few people with responsibilities for caregiving have been able to do philosophy unless those responsibilities were taken off our hands. In addition, or because of that fact, philosophy, its tradition and training, is very inimical to the sorts of lives our children (and indeed many dependents) lead, and the lives we lead together with them. Its tone is detached, abstract, and impersonal—it exists outside of the cave in which our lived lives are led. However, the bright sun outside Plato's cave blinds not only those who are not used to the sunlight; that is, those who just recently stepped out of the cave; but it can also obliterate important features of the landscape for those who long have dwelled in the sunlight—it can whitewash reality. Those of us who have the sorts of experiences of which Gottlieb speaks possess an advantage along with our handicap. When we try to look at the world in the sunlight, we continue to see the very real shape of many things too easily missed by others in the exposure of too much light. Even if philosophy whitewashes disability and therefore passes over children such as ours, with their impairments, with the special care they require, their lives direct us to the point and purpose of philosophy—the pursuit of wisdom. Their lives help us in our quest to discern what the meaning of life is; what makes life worth living or what makes a life a good life; what makes relationships ethical; what personhood is; how to understand beauty, anomaly, function, capacity, joy; what justice and equality are. I
have always, to some extent or other, seen philosophy as refracted through my experience with Sesha. It has taken me a long time to write about it.

I want to suggest that it is feminist scholarship and feminist philosophy that have made it possible for me to do so. We do feminist philosophy from our experience as women, or if we are men, from our commitment to a political ideal as we live it by means of and through the women in our lives. As feminist philosophers we have rejected as fiction the notion that philosophy is news from nowhere. We’ve spoken from a position, and on rare occasions we’ve spoken about that position. We do it when we feel that to do anything else is a retreat from truth.

The more I worked on dependency, the more it became clear to me that I must speak about Sesha; that unless I said plainly what motivated my thinking and my passion, I could not do my philosophy clearly—I could not put forward what I took to be the truth, or do so perspicuously. This is not a recipe for everyone. I think it was the case for me. It is a risk, a gamble that what one says is not seen as self-indulgence or a confessional or as only pertaining to one case. In fact, I have been astounded at the response to “Not My Way...,” the chapter on Sesha; I have been taken aback at the extent to which my discussion of what I had taken to be such an anomalous situation has had such resonance with people whose experience with disability is, at least on the face of it, so different.

Consider Gottlieb and his account of Esther. Esther, unlike Sesha, is verbal and clearly cognitively far less incapacitated. Her physical difficulties have many more medical consequences, although she is physically far more capable than my daughter. Gottlieb and his wife do not have an equivalent of Peggy, Sesha’s long-term caregiver, and at the same time, Esther is not nearly as fully dependent as Sesha. Yet Gottlieb’s account resonates with me. With suitable modifications, I know how to apply the questions and perhaps provide some answers from my situation. I’m not sure what such resonance says about the uniqueness of perspectives or the possibilities of speaking philosophically about disability. Surely not everyone with children, or even children with disabilities, can so identify with Roger’s account, and yet many can who have no children whatsoever. But in that case, what is special about speaking from a given position?

Sally points to the force of the book as residing in part from the “conjunction” of the theoretical, the social, political, and the personal. There is significant theoretical work to be done on why and when that conjunction is effective, when the characters and experiences in a personal narrative can take on representative significance, and when the exposition is merely self-indulgence. As her comments and reservations at the end of her paper suggest, it is also important to know when or how to guard against mistakenly thinking that the personal is representative, and thus a fair base for theorizing.
She contrasts her own more expansive understanding of caregiving with my more restrictive definition of dependency work. She mentions her concern that my principle of care may be too demanding, and that a tension may exist between emphasizing the work of care that motivates the restrictive definition and emphasizing the significance of the carer’s relationship and attitude of care to the cared for in the demanding principle. She points out: “Bringing a bed pan presumably does not require such an attitude [hence the principle of care is too demanding], but ‘significant friendship’ might well [the definition of dependency work excludes the caring we may do for a friend who is not especially dependent and so is too restrictive].” She identifies the use of my experience with Sesha as the source for my theorizing as leading me to create a definition that may exclude the “good enough carer” and fail to consider caring between those more equally situated. This question suggests to me that my own text requires some clarification. But I sense a deeper point that directs us to the danger of theorizing from the personal.

As a clarification, let me point out that I am trying to do several different things with these definitions and principles. The definition is as restrictive as it is only for the purposes of demarcating a certain paradigm, a paradigm that allows me to theorize from the assumption of a necessity that can neither be denied nor dismissed—namely, the care of those who are incapable of meeting their own needs as a consequence of age, illness, or disability. However a society is organized, a significant number of persons will be in such a condition. From that starting place we can then contemplate the requirements of those whose neediness diverges, in extent and kind, from this paradigm. The strategy is intended as a rejoinder to that of idealizing theories of justice as does Rawls, wherein the paradigm case is the fully functioning adult. This is not to deny that we do much dependency-type work for friends who are equally situated to us, nor that some dependency work is more about emotive responses to others than about emptying bedpans (as long as we don’t forget the person who empties the bedpans, just as we can’t forget that this aspect of dependency work is rarely adequate to the care of another person).

The demanding nature of the principle of care has to do with what I understand an individual to require not only to survive but also to thrive. It does not require that each dependency worker devote herself to this level of care, but only that each individual should have a right to the sort of care alluded to in the principle. Will some primary caregivers feel guilty that they are not providing such care, and am I therefore adding to the load of guilt heaped on women when they do not devote themselves to caregiving? Perhaps it is easy to read such phrases as “hold another’s well-being as a primary responsibility and a primary good” as insisting on more stringent requirements than I had intended. I only mean that each person ought to have access to the care of someone who really cares or who has a particular responsibility for us when are needy because
of “inevitable dependencies.” We cannot require that everyone who attends to a dependent really care. But we need to consider 1) what is required to enable everyone to receive a certain acceptable level of care when they are needy because of inevitable dependencies and 2) how those who hold the well-being of another as a prime good or responsibility (whether out of love or duty) may be provided with the right and capability (in Amartya Sen's [1987] and Martha Nussbaum's [1993] sense) to secure that good and fulfill their responsibility by doing hands-on dependency work or overseeing formally arranged care.

Perhaps with this clarification the principle may seem less demanding, less guilt-inducing for the good-enough caregiver. Or perhaps my experience with Seshan has led me to overstate the level of care to which a person ought to have access and the degree to which someone who wants to give care to a significant dependent should be given the wherewithal to do so. Generalizing from the personal too easily allows for the fallacy of induction from a single instance. Avoiding the personal voice, as we know, has its own danger. That is, when we ignore perspective, personal perspective can seep into our universalizations unwittingly, generating false universalisms. As Gottlieb has suggested, because neither the disabled nor those who care for disabled persons are well situated to do theory, in general, the issues that deeply motivated the concerns of the book are rarely heard in philosophy. Philosophy favors the objective stance, not the personal. By injecting my own singular voice I wanted to reintroduce perspective into an otherwise abstract and universalistic form of theory. But by doing so, I may have erred in overgeneralizing some aspects of caring and dependency particular to my case, and missed other aspects more commonly experienced.

How can we negotiate the personal, the political, and the particular on the one hand and the abstract, the objective, and the universal on the other? These are still more questions that a discussion of dependency opens on to and in which it participates.

Rosemary Tong's work here is another example of how much more territory questions of dependency embrace than I originally recognized. Tong directs us to the terrible irony that those who have been most responsible for doing society's dependency work come to be the least likely to receive good care when they themselves require care. In *Love's Labor* I try to promote a notion I call *doulia*, the public responsibility to provide support for the caregiver so that the caregiver can give care without depleting herself and her resources. I speak of the aphorism that might characterize the triadic concept of reciprocity embedded here: that what goes around comes around. But the aphorism seems sadly wrong—at least in our world. What's worse, it is precisely because of their caregiving labor that the women about whom Tong speaks are poor and unable to purchase the care they require as they age.
Tong introduces an element of inequality that I do not even remark on in my own work, but that needs to be addressed and rectified in any just society, certainly in one that espouses gender equality. Tong suggests universal health care, for starters, and I agree. But there is much more. Were those who do dependency work (whether women or men) able to participate in the benefits other workers receive for their labor (for example, to have dependency labor count toward Social Security, to be compensated, by insurance or stipends, for time taken away from waged labor to care for dependents, to have respite care available, and to have the same leisure time as those not engaged in dependency work), women would approach their last years better prepared for the disabling conditions that often accompany old age. Were women who want to continue in paid employment to have greater opportunity to purchase care at reasonable cost, while those who provide that care for pay were to have better working conditions, pay, and benefits, both sets of women would be better situated when they are older.

Furthermore, if providing dependency care were not simply assumed to be a familial obligation, but if dependents were themselves able to receive more support, familial caregivers would not be as depleted by caregiving as they currently are and might even be armed with a greater sense of entitlement to good care for themselves. That we lack universal health care and that hospitals send sicker and sicker patients home takes its toll on the familial caregiver, even when she is still healthy and able, leaving her the worse for wear as she ages.

One point that I want to stress is that the fact that most dependency workers are women as they age only compounds their difficulty for dependency workers as women are, in general, paid less and are vulnerable to sexual abuse and harassment in the workplace and at home. In addition, in most Western industrialized nations, they live longer. (Poor women in many developing countries are—shall we say—"spared" that complication!?) But even if men were to assume more of the dependency work than they now do—and I believe that the dependency critique directs us to finding ways of encouraging this—they too would be (and are, especially when they are solo parents) vulnerable to many of the same difficulties. The man who has devoted many of his so-called "productive" years to dependency care enters his older years poorer and less well equipped to demand care comparable to that received by other men. Even as we remain acutely aware of the gender dimensions of the problems addressed here, we also need to see that this is not entirely a matter of gender, but of the actual demands of a form of labor and the unjust social organization of that labor.

Tong adds a crucial observation: because the U.S. "health care system stubbornly separates medical care from social care," persons who need not be are nonetheless interjected into the [health care] system "simply for lack of funds
to pay for someone to do their grocery shopping and meal preparation for them, for example” (Tong, this volume, 207). I believe that what elders face here is a continuation of the medicalization of formal (that is, paid) care that disabled people have found so objectionable. Rather than see medical care as the subordinate term under the wider ranging heading of care, formal caring services are conceived of as a subdivision of medical care. Once again I think this is a manifestation of the pathologizing of dependency, rather the acceptance of dependency as a normal part of human life. Its expression comes through in the payment schedules of insurance companies and government entitlements. Formal childcare appears exempt, but then again, the only third parties who pay for this care are parents, save when they are indigent and receive welfare service, which is in turn pathologized as being “dependent on the state.” Societies regularly meet a variety of fundamental human and social needs by sharing the costs of trash removal, highway construction, policing, and basic education, for example. Once we accept dependency as a normal feature of a human life, all caring services that arise from inevitable dependencies including, but beyond medical needs, have no less a claim on the social sharing of burdens.

Now to the second of Tong’s “lingering doubts,” leaving the first for last. Tong admonishes me to complete the work I have begun by addressing how we can induce moral sentiments of care into a seemingly uncaring world. In moral theory, the assumption that claims of justice are claims of reason is longstanding, as is the view that we can influence the behavior of an agent by offering good reasons. Many theorists have assumed that developing good reasons and adequate principles according to which an individual can reason through a moral problem and so behave accordingly is the aim and purpose of moral theory. At the very least, we can expect a moral agent who desires to be just to act according to reason, even if she continues to harbor sentiments associated with unjust action. But caring, good caring, seems not only to involve the overt actions but also an attitude, a sentiment, or an emotion that accompanies behavior. Feelings, the standard philosophical wisdom has insisted, are not subject to reason, and because “ought implies can”, cannot be made the subject of moral persuasion or moral evaluation. What force do our reasons have against the indifference of uncaring persons? Like many feminist (and some nonfeminist) philosophers, I reject this strict separation of reason and emotion. Alison Jaggar (1989) and Martha Nussbaum (1999) make excellent arguments that I need not rehearse here. The project of achieving a just society, as conceived by Rawls, for example, could not get underway if people were to lack a sense of justice (which is itself a moral sentiment). Bringing about a caring world seems to me no more and no less difficult. In the same way that we must assume persons to have a sense of justice—albeit one that tends to be imperfectly realized—we must assume that people already
possess a moral sentiment of care. Both the assumption that people possess a sense of justice and a moral sense of care seem to be fair assumptions since it is difficult to imagine human surviving beyond a single generation without some sense of justice and without some elemental sentiment of care. Yet for a more perfect society, both the moral sentiment of care and a sense of justice require cultivation through education and practice, the success of which requires a political will. It seems to me that the difficulty is, first, to cultivate in men a sense of care as deep and extensive as we find today in women (Tong's second lingering doubt), and second, to join the sense of care with the sense of justice.

I say that the problem is to bring together the moral sentiment of care with the moral sentiment of justice, because in many societies, especially our own, the moral sentiment of care has been cultivated and largely restricted to the private or domestic sphere, while the moral sentiment of justice has been cultivated for the public domain. To a limited degree and with respect to a limited public, the political will to cultivate the sense of justice has been there. In the United States, for example, rights have been extended to increasingly large segments of the population. Reasons can be given, and I hope I have provided some, to believe that justice itself further requires the cultivation of the moral sentiment of care for the larger political body (and beyond political borders). The cultivation of a care linked to justice requires the resources of education, novels, movies, and other media and all the means we use to teach our children to be better people than we have been. The ultimate goal may be utopian, but working toward it can only improve our own lives and those of caregivers now too often abandoned in their old age.

Lastly, I address the question of how to get men involved in caring labor. I think that it is worth noticing that this is perhaps one of the newest demands that feminists have raised. We can go back to the medieval writings of Christine de Pizan's *The Book of the City of Ladies* (1944, II. 36) and find the demand that women be educated; to Mary Wollstonecraft (1988) to read her outrage at the infantalization of women; to the French Revolution for the insistence on women's full political participation; but even in the writings of late nineteenthcentury and early twentiethcentury feminists, who demanded equality for women on most fronts, little mention is made of men sharing child care or any other form of care work. Even Simone de Beauvoir (1952) assumed that childcare would continue as women's responsibility. Only in the writings of second-wave feminists of the 1960s and 1970s does the demand to share domestic responsibilities arise, and even there much of the hue and cry is over housekeeping rather than caregiving as such.

So I humbly respond that it will take a great deal more thought and effort than I alone can offer to crack this nut. The important thing is that the demand has now been made, and together we may be able to realize the
conceptual and political tools needed. Women may need to acquire much more economic and political power than we now have to make it happen. The Nordic countries may be the ones to watch. With tax structures and differential paid leave plans as motivators, they are attempting to alter child care patterns, reported George Nicholas in an article entitled “Swedish dads urged to take time off for children: An extra benefit incentive is being offered to get father to play a fuller part in childcare” published in London Edition, 23 June 2001. I also believe that compensating informal dependency work and dignifying formal dependency work with the benefits and status of desirable employment will bring more men into caring work—although these alone will not be magic bullets. Dignifying dependency work as something for which we need education, starting in the earliest grades for boys and girls, training that continues into post secondary school, and ultimately certification for those who do dependency work professionally will go a long way toward degendering this labor.

One man who has assumed a great deal of dependency work, far more than most, is Roger Gottlieb. Somehow, he nonetheless manages to generate an incredible amount of philosophical writing, and thus seems to belie our claim (as well as his own) that dependency work limits other productive work. In this paper, however, he also reveals some of the costs he pays to have a productive work life and not take care of just any child, but a child with very special demands.

I now want to address some the questions that Gottlieb poses with respect to his experience as Esther’s (and Anna’s) parent and to his invocation of spirituality. (Note that religion or philosophy of religion was not on my list of what I need to master to speak intelligently about dependency. Now, alas, I fear, I need to include it.) Gottlieb identifies five Western moral traditions: the Greek emphasis on natural development, the rights tradition of autonomy; the Marxist tradition of collective liberation; feminist mutuality and empathic connection; and the Judeo-Christian tradition based on submission to God’s will (Gottlieb 2002, 235). These, he remarks, all share a number of presuppositions that are problematic for people with (certain) disabilities and for people with experience as caregivers responsible for their well-being. Gottlieb avers that the religious one has the most promise for shedding light on the questions he identifies and the dilemmas he encounters.

Many of the dilemmas that he indicates are pertinent not only to those with disabilities and their caregivers, but to dependents and dependency workers more broadly. Consider the issue of political participation: My daughter is now thirty-one. While many of our adult children may choose not to vote, Sesha cannot vote. Yet Sesha has a stake in who is elected. Her life will be governed in good measure by the decisions of elected officials. Her father, and I, of course, can vote in her interest. But we are three people—each of whom has
an interest in the outcome: so we have three sets of interests (or alternatively we are interested parties), but we have only two votes. Now you might object that this is true for all parents with underage children. True. Yet this fact makes the point for merging seemingly disparate dependencies. If we, as a democratic nation, are interested in treating each person as an equal, perhaps we need mechanisms for ensuring that the interests of each individual are represented when we vote, and that each of the interests is given its numerical due. Let us say that both a child’s mother and father vote for an education appropriations bill. That is two votes. Yet it is not two persons who have an interest in that bill being passed. Each of their children do as well, but only two votes are registered in its favor. When fewer people choose to have children, and more people are living and voting past the age when school appropriations are of significance to them, the interests of children are surely shortchanged if only the adults have a (numerical) voice in the matter. Similarly, the interests of a thirty-one-year-old retarded woman go uncounted when she cannot vote or have a proxy vote for her. If there is an injustice in the case of one form of dependency, there is an injustice in the case of the other.

The Marxist problem of too many meetings raises similar issues for dependents other than the disabled who lack access to the meetings and their caregivers. Where is the voice of the child and her mother if the mother stays home with the child rather than attend the meeting? What about the voice of the ill person who cannot make it to meetings? How do we ensure that these interests are acknowledged?

Again, regarding the constraints on friendships, not only do parents with disabled children face isolation, but so do caregivers in general—caregivers for ill persons, for young children (especially in suburban communities and whenever a caregiver undertakes a dual workload). Dependents frequently come to depend on their caregivers for companionship as well as care. The one-way giving of care that marks the dependency work for a fully dependent person, and which can become very depleting, is similarly shared by those who do dependency work for different populations. Cases differ, however, both in kind and in degree.

Differentiating dependency resulting from significant disability appears to be most called for when considering the Greek emphasis on natural development. Gottlieb says that here the problem of disability is that it represents a kind of ill health, and that a “radically different model of health is required” if disabled people are to be included within its model of moral life. He writes: “The melancholy truth is that disability and the care for disability limit our capacity to understand and to act in the world” (Gottlieb 2002, p. 228). I want to suggest further that “the melancholy truth” is that we are always limited in our capacity to understand and act in the world—that we are always in the process of losing capacities and gaining others. I do not believe that a “radically
different model of health is required.” I think, however, that a radically different conception of what is “natural” for humans needs recognition, and also a radically different understanding of where the obligations lie for dependency care and for enabling individuals to lead flourishing lives even when some of their functions are impaired. Why do I want to stress the commonality of different forms and kinds of dependency care? This has to do with what may be different approaches between Gottlieb and myself. I want us to see disability as sometimes (though not always) resulting in a dependency that is but one variety of a dependency that we have all experienced at some point and to which we are all vulnerable. Similarly, the care of the disabled person who needs to be assisted is but a form of care that many persons give to dependents of all sorts. My reason for eliding the differences in favor of the commonalities is that I believe that we as a society have to end our fear and loathing of dependency. We need to see our dependency and our vulnerability to dependency as species’ typical.

This is not an easy insight. For some it is bought at a dear price. In a recent interview, the comedian Richard Pryor (1995) was asked to speak about the Multiple Sclerosis that has incapacitated many of his bodily functions and will accelerate his death. Pryor said that as he lost old capacities, he had to learn new ones. Indeed, he maintained that the Multiple Sclerosis was “the best thing that had ever happened to me;” that his disease has been the occasion for the most important lessons he has had to learn about himself. He said that when, in order to walk from one end of a room to the other, a person must depend on another, he learns how to trust. Learning to trust when he was vulnerable was the most valuable lesson he learned. This is a knowing that can alter us profoundly, especially when independence is touted as the hallmark of personhood.

When we alter our focus and see dependency as unexceptional, we also have to consider just and caring ways to distribute the cost of dependency, and the burdens of dependency work.

I want to see not only a great deal more social responsibility and responsiveness considered for disability in particular, but for dependency in general. To single out disabled people is to continue the stigma under which those with disabilities and their families have had to live. To identify the needs of those with disabilities and their families as politically exceptional is to narrow the constituency for change and the base for political action.

The difference between my approach and Gottlieb’s may or not be related to the spiritual dimension that he introduces. I always have some difficulty with religious traditions because I have not chosen to walk down that path. Yet when Gottlieb speaks of his daughter as being the most spiritually advanced person he knows, I can connect, for Sesha brings me and those who know her well into a different spiritual dimension. Hers is a remarkable spirit. We can
only speculate how much of her special quality is a consequence of her dis-
ability and how much is just the person she would be regardless of disability.
Her disability has protected her from much that is nasty and unpleasant, but
it has doubtless also been the source of pain and frustration at the difficulty of
communicating her wants or needs. Yes, there are times I feel acutely pained
by the limited life she leads; I wonder if she sees children running and wants
to do that. I wonder how left out she feels when conversations whiz by her
and she is neither addressed nor would be able to respond. Maybe I, too, want
to be angry with God. But more frequently I am angry at man: angry about a
society that leaves all the responsibility for the care of children such as mine
and Gottlieb's on the shoulders of those to whom they happen to be born, at
the refusal to recognize a shared responsibility to meet the needs of dependent
persons. If Gottlieb and his wife were properly supported in their dependency
work, the difficulties they face in giving adequate time and attention to their
nondisabled child would not disappear entirely (life is not perfect), but it would
be significantly mitigated. In this situation one should not rage against God,
but against a callous society, a society that fears and wants to hide from depen-
dency and the full scope of human variation rather than to acknowledge and
embrace it. Yes, there are social causes for disability, such as environmental
toxins, automobiles not built for safety, drivers who drink when intoxicated,
unsafe workplaces, and unsafe toys. But the social causes of disability also
include the failure of adequate environmental modifications that would enable
people with impairments. And they include the prejudices and discrimination
that isolate and stigmatize both the disabled and their families, creating condi-
tions that are as, if not more, disabling than the physical/mental impairments
themselves. If we move to a spirituality, let it be one that also turns outward,
that locates the alterable social causes for misery, the injustices. We all have
drawn short sticks somewhere in the lottery of life—that is not an injustice.
It is the social responses to fates we happen upon that result in the injustices
we decry.

Notes

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References


