Discussions of the impact of disability on women almost always reveal troubled relationships between disabled people and the women who care for them, whether the caregivers are intimates or professionals. Often there are similarly troubled relationships among caregiving women themselves. These problems are intricately connected to other difficulties with sisterhood that have been more directly addressed in feminist theory.

My own experience as the mother of a young woman with both physical and mental disabilities is not reflected at all in feminist literature, even though mother-daughter relationships are often discussed there. Likewise, in literature about disabilities, the feminist implications of our situation are seldom addressed. When Jennifer became an adult and she and I had to work to understand what that means to someone who is mentally retarded and "dependent," I looked for ways of integrating my feminist philosophy with our struggle for survival. What I have learned has important implications for feminist theory, partly because the experience of women with disabilities and of those who care for them is so deeply felt. The emotional depth that resonates in the best feminist theory is intrinsic to our lives.

Relationships among women in the care and treatment of disabled people are greatly complicated by social expectations about "handicapped" people, about women (especially mothers and daughters), and about professional caregivers. All of these expectations, often deeply internalized, are closely related to stereotypes of femininity and are quite handicapping both for the woman with disabilities and for the woman who cares. On the other hand, women's traditional values and morality provide a potential for great strength in these relationships and for an important expansion of feminist theory.

Independence, Productivity, and Handicap

Basic to working out relationships among women in connection with disability or handicap are social expectations about dependency and independence. Both professional and popular literature define dependency as a problem. For the disabled person, the problem is how to cope with being dependent. For caregivers, it is frustration and fatigue from caring for the dependent other. This reasoning is based on the dichotomy between masculine independence and feminine dependence as if only the polarized extremes were possible or desirable. The dichotomy is strongly reinforced by the cult of the body that at least implies that adequate adults will be strong and "fit," especially in physical, but also almost incidentally in emotional terms. The notion that the possessor of one trait cannot participate in its opposite leads to excesses at both extremes by people with disabilities and by their caregivers as well.

Of course, a disabled woman may merely subside into pleasant, feminine passivity, accepting her inability, say, to jog as representing a more generalized inability to be responsible for her life, but she may just as disastrously refuse to develop any realistic understanding of her own body. For example, a few years ago when I facilitated a discussion of disability and dependency at a feminist meeting, several participants expressed great admiration for a paraplegic woman they had heard about who insisted on building her own house without the aid of a contractor or other able-bodied help. No one questioned the possibly inappropriate or excessive quality of her "independence."

Audre Lorde presents the external pressure toward both of these extremes in her own experience after a mastectomy when the hospital's bland reinforcement of her...
passivity made her feel like “totally inert, emotionally vacant, psychic mush,” and the people designated to help her “adjust” insisted that she should deny the reality of her changed body by wearing a prosthesis and behaving as if she were unchanged.  

For the female caregiver, the dichotomized expectations are self-contradictory, since caring requires that exceptional physical and emotional strength be exercised in traditionally feminine occupations that require subordinate behavior (housewife, nurse). She is expected to be available, dependable, and constant; to give structure to a potentially chaotic world. At the same time, these behaviors may be seen as threatening or emasculating, especially, but not exclusively, if the disabled person is a male. Moreover, she may be discouraged from expressing the qualities normally acceptable in women, such as displaying emotional responsiveness.  

Closely related to the emphasis on independence is our strong social ethic of productivity, which has very serious implications for disabled people and accounts in part for stress in relationships among women who care for them. When disabilities limit the productivity of one person, there is a corresponding pressure on others to make up for the loss. Parents and teachers are encouraged to work at giving the illusion that the disabled person is independent or productive, and they may therefore strive to shift this burden to each other or to other professionals. A teacher of children with disabilities may, for example, be judged successful if she transfers an increasing share of instruction to the mother to be done at home. Infant stimulation programs sometimes require ten hours a day or more of intensive work with a child at home.  

Mothers of disabled children are held more accountable than others to an externally defined concept of adequate mothering because of their increased contact with social agencies, medical institutions, and special education. Yet their experience is actually more chaotic and less manageable than most. For example, staff members in institutions for emotionally disturbed children and for retarded children have criticized mothers for being unable to handle at home children whom they themselves have great difficulty handling in the institutional setting.  

For the intimate caregiver, care for herself may run counter to an important personal (and feminine) value: care for others. Therapists or counselors may encourage a mother’s “self-actualization” as if the dependent other were not part of herself or as if there were no institutional barriers to relief from full-time responsibility for that other person. Both intimate and professional caregivers frequently suffer from burn-out. Both may make substantial personal investments in a severely disabled person without being rewarded by improvement.  

Relationships between disabled women and women caregivers are often even more troubled. If the disabled woman does not play out the feminine role, she may threaten the caregiver’s own feminine self-concept and, at the same time, her “masculine,” strong, and dominant role as the independent opposite of the disabled woman’s dependent stance. Our society’s excessive emphasis on independence undermines the disabled woman’s relationship with her female caregiver by increasing the resent-

ment of proffered help, whether or not it is needed. Resentment of help may increase the caregiver’s burden; the social legitimacy of such resentment may inhibit the articulation of the caregiver’s own needs.  

On the other hand, disabled people are sometimes made more dependent than they need be by the caregiver’s need to be needed. Thus, the caregiver may be required to be more than adequately competent and productive, filling her own quota for these qualities and at the same time providing services that will enhance or replace such qualities in the disabled person. At the same time, the disabled woman may be required to be less than adequately competent and productive in order to enhance the caregiver’s self concept as one who is needed, thus insuring continuation of her services.  

It is interesting to look at the concept of “handicap” in this connection. A physical attribute is a handicap only when it is seen as a significant barrier or when it has an adverse effect on relationships. In this definition the physical disability may be a handicap to both the disabled person and the caregiver. Indeed, if the caregiver (a mother or daughter of the disabled person) is perceived as inseparable from the one she cares for, her physical, mental, or emotional fitness may itself be a handicap. For example, I know of two women who added the work loads of their mothers to their own career and childrearing responsibilities when the mothers were disabled with Alzheimer’s disease. Although they recognized that their mothers were no longer able to perform or even understand the work they had done before, the daughters were expected, and expected themselves, to maintain such traditions as providing meals for the harvesters and the church group simply because the mother, who was still alive and physically present, had always done so. The daughters are able to do the work; they adopt the mothers’ commitments, inappropriate to their own lifestyles, as if they were their own—and in addition to their own. In these cases, the caregiving daughter is handicapped because her ability to do the work of two places a heavy burden of productivity on her and because such superhuman responsibilities increase the stress in her relationship with the disabled mother and with others.  

Where the disabled/caregiving pair are mother and daughter, an exaggeration of “normal” separation needs is combined with exceptional intimacy, often empathic or “symbiotic.” My adolescent daughter needed to separate from me as much as her able-bodied and -minded sister did, but she had none of Megan’s survival skills. Jennifer needs around-the-clock adult supervision for her own safety. Since she cannot articulate her emotions, she relies for protection on her caregiver’s ability to interpret them for her and to prevent her expressing them in self-destructive ways (for example, by running into traffic or jumping out of a moving car). Our relationship during her early adolescence was symbiotic in that I could empathically understand her distress and she provided an almost purely emotional balance to my tendency to intellectualize. Her need to separate from me, the one who interprets her world to her and to others, was in a sense self-destructive, since it left her unprotected and uninterpreted.
When a psychologist described this relationship to me as "symbiotic," I had difficulty with the concept, not because I denied our exceptional intimacy but because the dependence was so unbalanced. She needed me for survival; my need for her was less basic, more complex. The concept of symbiosis is commonly used in developmental psychology to describe the relationship of infants to their mothers. Benedek and Balint have observed that male psychologists fail to acknowledge the asymmetry in this relationship—the same asymmetry that I experienced with Jennifer. Transferral of the concept of infant symbiosis/individuation to disabled people outside of infancy increases the probability of such distortions.

Against the social and personal pressures epitomized in the issues of independence and productivity, both disabled women and women caregivers need a clear understanding of their situation as women to enable them to develop a reciprocal relationship, an understanding that meeting needs need not be so one-sided.

**Feminist Theory**

To bring together women's experience of disability with feminist theory requires a thorough reexamination of both which I can only suggest in a short article. All feminist issues are encompassed; all "knowledge" about disability must be reevaluated. Only a few key areas are addressed here, as a beginning.

The concept of "boundary living" has particular relevance to disabled women and the intimates who care for them because both have more than average contact with patriarchal institutions and less than average choice about which ones. These typically include medicine in many of its subinstitutions; government, including law, welfare, and other social service departments; education; and religion. Often these institutions overlap, as in treatment facilities operated by churches who also offer public school special education classes under their auspices. Women seeking access to treatment must accept the total package in such situations. Regardless of the women's preferences, they are dependent on these institutions for services. Outright resistance to the institution's philosophy or to its usual way of doing things may cause partial or even total withdrawal of those services. Mothers of hospitalized children report strongly negative reactions from staff members if the mothers declare their own needs, especially if the child is "hard to handle." Mary Daly's suggestion that feminists must decide which institutions' boundaries they will inhabit may seem cruelly ironic when life itself is at stake. Whether the boundary is freely chosen or not, however, an intensive exploration of how to maintain the stability of one's center on the boundary while conserving the energy needed for survival is crucial, and it must be exercised despite the centripetal force of the institution and the temptations to become entirely passive or even a collaborator in the institution's values.

Recent feminist discussions of women and nature emphasize the closeness of women to life and death and to the individual quality of human development, positing that women are more experienced with change, both positive and negative. Recognizing the complexity of individuals and of their interrelationships, women are more likely than men (and thus more likely than male-designed institutions) to recognize that all people need help in development at all stages. Experiences of disability that may enrich the development of feminist theory on this point include the recognition that death is not always the worst thing that can happen to a person; that senility and degenerative diseases undermine belief in life as a growth process; that full, internalized acknowledgement of the body's "real" condition permits the elimination of phony or excessive heroism; that human beings are limited; that some losses cannot be repaired; and above all that female strength and weakness must be integrated.

For both the disabled woman and the caregiver, achieving these insights involves an intensive, integrated, emotional, intellectual, and physical process of self-centering that includes recognition of the reality of the problem and the experience of grief. At least since Mary Daly's *Beyond God the Father* was published in 1973, a basic tenet of most feminist philosophy has been that "transcendence" comes not from denying but from coming to live from within one's self. For all of us the difficult work of finding this self includes the body, but people who live with disability in a society that glorifies fitness and physical conformity are forced to understand more fully what bodily integrity means. As Adrienne Rich observed of childbirth, avoidance of pain and ignorance of our own bodies leaves us out of touch with ourselves, our own limits, our transience.

To be in touch with one's limitations, as people with disabilities are forced to be, makes one feel less safe. To examine the meaning of this lack of safety is to explore the nature of one's own "real" condition—not idealized or misinterpreted by the culture. Women, Jean Baker Miller says, can develop a different understanding of weakness and the paths out of it if we learn to work with our feelings of vulnerability. For women with disabilities, the greater temptation may be to be swamped by these feelings; for caregivers, to deny them entirely. But because both experience both temptations, they have at least the potential for working together on getting through the vulnerability to the underlying central identity of each individual. In a culture like ours that values optimism and a cheery willingness to minimize difficulties, it is very difficult to see oneself as a person with a serious problem. Yet that is exactly what is required of anyone who must live with a disability, whether the cause is physical or social or both. Recognition that she is a person with a serious difficulty defined from within forces a woman to find significance in her life as it is. If both the woman with the disability and the caring woman acknowledge their vulnerability and the seriousness of their separate but related problems, they can collaborate in working on the paths out of weakness. Such collaboration, including creative conflict, may help us change the definition of dependency.

Excessive insistence on one's own independence is an understandable reaction to being defined as dependent or incompetent. The reaction is common in the women's movement and accounts for the feminist ideal that em-
phrases physical fitness and mechanical competence, a model that is especially difficult for a woman with disabilities to adopt. She may therefore have more incentive than people who can approximate that image to define herself as an individual whose identity comes from within and not from any social ideal, not even a supposedly feminist one. As she does so, she may well encourage her caregiver to undertake a comparable reevaluation of her own superwoman routine.

Feminist theory has given considerable attention to the necessity for confronting existential questions—the void, the dark center of the self—and to recognizing the complex emotions surrounding female subordination. A related confrontation that has received very little attention in feminist theory and that is of crucial importance to people who live intimately with disability is grief. The fact of unusual empathic intimacy between the caregiver and the person whose disability occasions grief for both may, if it is not blocked by the decorum of illness, enable them to compare their experience of grief and see how it is shaped by their differences and the different external pressures on them. Recognition of the chronicity of grief and its place in one's central values counters romanticized versions of nobility and suffering and false expectations either of permanent mourning or of the normalcy of grief “stages” derived from observations of bereavement. Beatrice Wright has suggested that we impose mourning on disabled people as a defense of our own values. For example, if a woman cannot use her legs but refuses to mourn for the loss, we may be forced to ask questions about why we place such a high value on walking around. If a woman with a chronic illness adapts her pace to her illness and does not grieve over the loss of a conventionally rapid pace, we may have to question the high value we place on rushing around. Margaret Voysey, on the other hand, reports that parents of disabled children need social legitimation of their suffering because the pressure to behave as if their situation is “normal” overwhelms their trust in their own feeling that it is out of control. The process of understanding one's grief involves an understanding of these external pressures as well as a willingness to experience one's own pain. Acceptance of oneself as accessible to suffering is surely part of that existential courage that Daly says women are called to bear.

One reason for the great difficulty most of us have in working out ways of changing dependent/caregiver relationships is our logical reliance on the concept of equality—that people should be treated the same—an ideal that is especially difficult to attain when one person can walk or see or hear or reason and the other cannot. Carol Gilligan points out that this premise is basic to the ethic of justice that characterizes the highest value in masculine morality, but women's morality places a higher value on an ethic of care, whose premise is that no one should be hurt. Gilligan argues that both perspectives converge in maturity for both sexes. If we examine the disabled/caregiving pair in the light of Gilligan's analysis, we can see that reciprocity would require understanding of the caregiver's need for equality as well as the disabled woman's need for care and vice versa.

Disabled people force us to face the problem of reciprocity, the investment in a relationship by both participants. Reciprocity involves the difficulty of recognizing each other's needs, relying on the other, asking and receiving help, delegating responsibility, giving and receiving empathy, respecting boundaries. It also involves, as Eleanor Roosevelt pointed out, the ability to accept what we are unable to give and what others are unable to give, a much harder doctrine. Feminists who live with disabilities tell me that they are especially frustrated at others' unwillingness to believe them when they describe very accurately what they cannot do. On the other hand, when women with visible disabilities say clearly what they can do, in the same feminist groups, their offers are frequently ignored or minimized. For caregivers these problems are compounded. Since the disability that limits them “belongs” to someone else, it may be interpreted not as a limitation but as an excuse. Moreover, since women are taught to place a high value on giving and to avoid even the appearance of selfishness, it is hard for us to receive help or ask that someone else meet our needs. And it is correspondingly easy to judge a woman who says she is unable to give but needs care from others. My point is not merely that we should change these patterns, but that the reciprocity worked out between a woman with disabilities and a caring woman can serve as a model for the rest of us only if we attend thoughtfully to what they have learned and believe them when they tell us about it.

Romanticization of the recipient of help and of such notions as strength through adversity is not reciprocal, since it holds the other to a higher standard of ability to suffer than oneself. One painful aspect of mothering a seriously disabled child is living with the frequent well-meant comments on how admirably strong one is for coping with such a difficult problem when, in fact, the situation seems out of control and one is just barely coping. Another is receiving unrealistic praise of the child's “progress” or “normal” qualities when the mother knows that the child is not progressing or normal. I am almost undone when people single out Jennifer's beauty for comment, since it is not only irrelevant to the difficult problems posed by her disabilities but is also an ironic commentary on the social value we give to physical appearance. Far from making her life easier, her prettiness is a disadvantage when it enables people to overlook her real needs. Saying that I am wonderfully strong because I can bear a tragedy that the speaker could not bear does not merely deny my reality; it also measures me against a standard (one who suffers bravely) different from that by which the speaker measures herself. Saying that the child is progressing when she is deteriorating and urging me to agree denies my reality and requires of me an irrational optimism that makes me responsible for the other person's comfort.

I suggest that women with disabilities and those who care for them can work out a model of reciprocity for others, but of course this is not easy. A serious problem, especially when the disabled person is a child or is mentally or emotionally handicapped, is that the person needing help lacks a realistic sense of the caregiver's needs.
If the caregiver can see articulating her own needs as training in reciprocity, the imbalance in this situation may be partially redressed while at the same time the woman's ethic of responsibility for the dependent other is honored. Miller points out that subordinates usually lack a realistic evaluation of their own capacities and problems; training in reciprocity may, therefore, be a significant strategy for modifying the dominant/subordinate relationship between disabled people and caregivers.

One premise of feminist therapy—that a primary goal is equality in the client/therapist relationship—is an important key to restructuring asymmetrical relationships among women in other situations. As Martha Thompson observes, building on Rich's theory, when relationships between women are primary and reciprocal, including an exchange of both tangible and intangible resources, we will be able to make a profound commitment to not draining each other of our resources.24

This above all is what both disabled women and those who care for them ask of each other; together they ask it of the feminist community. These women often lack, even in feminist groups, that community of like-minded women25 that is necessary for women's health and even, sometimes, survival. As Miller observes, growth requires engagement with difference and with people embodying the difference.26 A diverse, experienced, frequently invisible group embodying a wide range of difference, these disabled and caregiving women are a valuable resource for feminist growth and change.

NOTES

1. It is no coincidence that one of the more challenging probes of problems in feminist relationships was written by a woman who has experienced a serious disability or that it addresses issues of dependency. Joanna Russ, “Power and Helplessness in the Women's Movement,” Sinister Wisdom, 18 (Fall 1981), 49-56.
3. Evelyn West Ayrault, for example, warns that the mother of a handicapped adolescent must not let the child perceive her own grief or anger. See Helping the Handicapped Teenager Mature (New York: Association Press, 1971).
7. Ayrault roundly condemns the mothers of handicapped adolescents for considering their own convenience in performing domestic chores if this involves making decisions about where the child should be while those tasks are being performed (p. 102).
10. There are a few institutions where the values of women have had a positive impact on policy. Shelters for victims of domestic violence and some parts of the hospice movement are hopeful examples.
13. I am indebted to Dorothy Dinnerstein for the idea that lacking a feeling of safety may be a positive condition. The Mermaid and the Minotaur (New York: Harper & Row, 1976), p. 136.
16. Pauline Bart has pointed out that this model is that of an adolescent, working-class, Gentile male, an image that is inappropriate for many—perhaps most—women. Cited in Letty Cottin Pogrebin, “Anti-Semitism in the Women's Movement,” Ms., X, No. 12 (June 1982), 66.
20. Daly, Beyond God the Father, pp. 23 ff.
23. Miller, p. 7.
25. This idea does not mean a “support” group, but rather a group of colleagues who have thought through the same issues.