The Private and the Public: Family Ideology & Care of People with Disabilities

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The gendered nature of care giving of the disabled is discussed against the background of feminist positions on care and paid work. It is argued that the private/public divide persist and that traditional family ideology serves to create a double or even triple bind as most care giving is done by women. An overview of research literature, popular literature and materials provided by support groups illustrate the extent to which this ideology persists. It is argued that we have to challenge the notion that care is primarily women’s work.

An increased life expectancy, coupled with the ageing of the baby boom generation, is impacting disability demographics. At the same time, advances in intervention after stroke and head injury are increasing survivor rates. Prior to 2001 estimates were that one and a half to two million people in the US will sustain brain injury every year, with 70,000 to 90,000 experiencing long-term impairments. The lifetime cost of long-term care per individual can exceed millions (Degeneffe, 2001). More recently, the war in Afghanistan and Iraq has caused a spike in the number of head injuries. In most cases it is within the context of family that stroke and head injury survivors and other disabled people, are taken care of. Injury, disease or disability does not only affect the person requiring care—the caregiver likewise takes on a new role.

In this paper I discuss the gendered nature of care giving against the background of feminist positions on care and paid work and show how the private/public divide persists. I argue that pervasive family ideology in the literature on care giving in academic journals, popular literature and materials provided by support groups continues to marginalize women caregivers.

Care is Increasingly Becoming a Family Affair

The shift towards inclusion of families in rehabilitation, therapy and care of the disabled coincides with a gradual move in medical care towards a more inclusive model. More patients are asking to be seen as partners and a more holistic model of health care is increasingly being demanded.

There is a general expansion of family driven models of supporting persons with disabilities, including acquired brain injury. Over 60% of persons with developmental disabilities live with family caregivers (Gan

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Language, occupational and physical therapy is geared toward ‘community re-entry’ and ‘activities of daily living’. Even cognitive therapy is moving away from clinical settings towards a model based on home environment.

The shift towards homecare impacts many families—for example, 80% of the approximately 5 million stroke survivors return home and there are estimates that as many as 74% of these people require assistance from layperson caregivers for activities of daily living (Kalra et. al., 2004). In the US there are approximately 52 million informal caregivers who take care of people over the age of 20 (National Caregivers Association, 2007). Three quarters of them are female (Crawford & Unger, 2004); they are wives, mothers, sisters and daughters and most of them are older women. In fact, in research literature, ‘family’ becomes a code word for ‘mother’ (Spiegel, 1982).

The greater involvement of family and the trend toward home-based care seem to represent a positive move toward greater inclusiveness and a greater awareness of the patient or disabled person as rooted in a social network. At the same time economical forces are at play in a profit-driven medical system. Thus home based care is becoming a necessity, not a choice. In the US, health care is to a large extent in the private domain. Social services have gradually been eroded and public funding available for the care of people requiring care is decreasing.

The language of cost-effectiveness is repeated often, with calls for models that maximize information delivery while making the most of health professionals’ time. While doctors are facing mounting pressure to reduce length of stay of traumatic brain injury patients, they are also pressured to limit referrals and time spent with each patient (Holland & Holland, 2002).

Two seemingly opposing forces are apparent: Family is involved in care because of a greater awareness of the importance of the social network of the patient or disabled person. At the same they have no choice: The burden of care is shifted from the public domain to the private.

Against this background, the profile of the home caregiver takes on a new significance. The identification of women with the caregiver role mirrors the identification of women with the housewife role that earlier feminists wrote about. In fact what we know about caregivers seems in many ways a description of housewives lives half a century ago (Andersen, 2000; Sapiro, 2003). As described by Friedan (1963) in *The Feminine Mystique*: Home care giving is similarly a taken-for-granted, unpaid role, taken on willingly. Consider the advice given to caregivers in McLeod’s (2002) *Caregiver Companion*:

> Many caregivers feel torn between their care giving responsibilities and their family obligations. Balancing the two takes effort, but it is important not only for preserving family relationships but also for protecting the caregiver’s emotional
resilience. As your care giving situation evolves, your spouse and/or children may need reassurance that they, too, are priorities in your life. Perhaps the best way to demonstrate your commitment to them is to give your undivided attention to each person, even if only for a brief period every day. (p.364)

Later on she says, “Taking time for yourself replenishes your mind and body. And that makes you an even better caregiver” (2002, p. 365).

Care giving is a master status, that is, the status that dominates all others and thereby determines a person’s general position in society (Hughes, 1945). Care giving as master status has financial implications for caregivers, as well as health and psychological implications. The isolation of caregivers seems to mirror the maternal isolation that feminists wrote about—the physical isolation that Millet talked about or the psychological isolation as described by Rich (cited by Chodorow & Contralto, 1982). The perceived privacy of family matters further inhibits caregivers from seeking assistance or information. All this serve to limit women’s opportunities for self-realization and self-fulfillment. Clearly, a feminist analysis of care giving is called for.

Public & Private

The dichotomy between private and public lies at the heart of the discussion around care giving—the ‘personal is political’. We generally take the division of the social world into ‘public’ and ‘private’ spheres (Gittins, 1985) for granted. This is, however, an important ideological construct, which reinforces inequalities between people. The concept of ‘private’ is linked to a stereotype of family, home, or domestic life, while paid work and economy are ‘public’. With reference to care giving of the disabled, the distinction also applies to ‘experts’ (in medicine, scientific research, policy-making) and ‘non-experts’ (individuals affected by disease).

The family encapsulates and embodies the private sphere but is also an object in the public sphere open to manipulation. Families are held accountable for public policy issues such as health and the development of children. Whereas children’s upbringing falls largely within the ‘private’ sphere, their health is both private and public.

Care of disabled people is increasingly becoming private. As such, it is relegated to the world of unpaid, less valued work, mainly performed by women. At the same time, the ideology of family is being perpetuated in both popular culture and academic work. Motherhood is glorified, love and consensus as the basis for family relations is emphasized and the notion of the family as a domestic refuge and haven (Lasch, 1995) is maintained. The functionalist view of family persists, not only in popular thinking, but also in sociological textbooks—families are seen to serve society by raising children, caring for the elderly and caring for the
In reaffirming the role of family in long-term care, we are reinforcing traditional gender roles. In a time of much public debate around the crisis in health care in the US, we are relieving the medical establishment of a commitment to provide optimal services for the disabled and the public sector from responsibility for the well-being of individuals in society. Providing care at home, moreover, has important financial implications for women (and their families).

**Financial Implications of Home Care Giving**

Both men and women report lost opportunities for promotion and career advancement, but the gendered nature of care, especially in the case of the elderly population, has important financial implications. Employed women provide as much care as the unemployed. Taking care of a family member has career and financial implications for those in the paid labor market.

Female caregivers find themselves in a complex bind: Women as a group are at a financial disadvantage. The burden of care is shifted to family (still, by and large, the domain of women) under the assumption that they are willing and available to provide care. Providing care puts them at an even greater financial disadvantage. In gerontology, the *double jeopardy* thesis portrays women’s aging as a problem. Two subordinate positions multiply the disadvantage. The assumption is that prejudices and discriminations against a minority group are worse when combined with prejudices against another disadvantaged group. A combination of sexism and ageism problematizes women’s aging. Older women find themselves in a weak financial position (Krekula, 2007). If we take the financial implications of care giving into account, the double jeopardy, in the case of caregivers, turns into a *triple jeopardy*. Against this background we will now examine the feminist view on care and paid work.

**Feminist Views on Care**

Of the many feminist schools of thought, three theoretical perspectives are particularly relevant in a discussion around care giving and will be discussed briefly. The first is the relational school, which argues for the need for society to be more ‘feminine’ or caring and which demands greater recognition, validation and social support for work done in the private domain. Liberal feminists, in contrast, argue that a dichotomy of gender roles which assigns the caring role to women is a social construct perpetuated through gender role socialization. Marxist and socialist feminists differ in fundamental ways from both these schools of thought. They see the family as a site for reproduction of labor, where women’s unpaid domestic work and child care directly benefit the state—they also care for those who are not in the workforce—children, disabled, elderly and chronically ill. These theorists argue that care delivered in the private
sphere sets the scene for the exploitation of women.

In the feminist movement, care is seen as emotional as well as physical labor. Feminists have done very important work in the fields of maternalistic rhetoric and imagery—the desire to preserve life and foster growth are seen by many feminists (for example the relational school of thought referenced above) to serve as a blueprint for human interaction that would involve peace and security. Thus the concept ‘care’ is valued. Judith Evans points out that in everyday language the words care and caring connote positive emotions. She argues (1995) that we should distinguish between action and emotion (care, care about). Gilligan postulates a female approach to moral issues based on caring qua emotion: “An Ethic of Care.” People do not make choices only for individual reasons—in fact choices depend in part on the consideration they give to the welfare of others. There is an important connection and relational self to women’s sense of morality (Gilligan, 1982; Lewis, 2007).

Feminists like Gilligan argue for the need of society to be more ‘feminine’ or caring. Nurturing is not seen as a uniquely female condition—but through the process of socialization boys are disconnected from their nurturing nature—as privileged, dominant members of society. Thus the politics of dominance persists. Women, on the other hand, maintain their nurturing nature. Relational psychology teaches us that all our experiences are of relationships, never of unrelated selves or individuals. The concept of a separate self is questioned—healthy women are found in strong, lasting relationships. Good relationships provide zest (vitality, aliveness, energy), power and effectiveness (empowerment), knowledge of self and others, a sense of worth and a sense of greater connection and desire for even more connection (Robb, 2006). This would partially explain why women take on caregiver roles almost without thought.

The problem, therefore, does not lie in the performance of these roles. The tasks assigned to women by the dominant culture are deemed essential: Raising children, caring for the old and the sick, serving sexual needs—but in our society they are defined as marginal and inessential to the ‘real work’, which men are supposed to do. As Robb puts it: “They [women] do many of the things the culture holds up as being good – helping others, giving care, giving service, going with the flow – yet they often don’t feel good about it” (2006, p. 56). Greater recognition, validation and social support for care work done are needed to elevate the importance of the private domain. At the same time there is a need for men to reclaim their nurturing nature, which would lead men to take on more care work as well.

This perspective is not shared by all feminists. In fact there is ambivalence in feminist writing between values of nurturance and collectivity, strongly association with women and family and values of individualism and equality, supposedly derived from a capitalist market—values that women have historically been denied and are claiming. In this same
vein, caring has typically been defined by feminist researchers as the unpaid work of kin within the private domain of the family. Social relationships based on gender shape the organization of care (Graham, 1991). Folbre and Himmelweit (2000) likewise point out that the treatment of women in society has always been linked to the ways care is provided to children and other dependents. Watson and co-authors argue that care and caring are activities that are socially constructed rather than ‘natural’. Their position is that notions of the ‘natural’ construct and colonize gendered experiences and meanings of care. “Women who care are thought to be exercising their natural proclivities to nurture and this invidious assumption translates into low wages” (2004, p.338). Liberal feminists would see women’s automatic assumption of the care giving role as the result of socialization and one more barrier towards their emancipation. The policy demands of liberal feminists focus on a demand for greater support from the public sphere (which includes government).

Finally, Marxist feminists like Heidi Hartmann (1984) see the family as a locus of struggle. According to her, family cannot be understood “solely, or even primarily, as a unit shaped by affect or kinship, but must be seen as a location where production and redistribution takes place (Hartmann, 1984, p.342). The redistribution in family is necessitated by divisions of labor inherent in the patriarchal and capitalist mode of production. She sees family as a unit but looks at the members as gender categories with particular relations to the division of labor organized by capitalism and patriarchy. Her work provides a useful model by distinguishing between production issues and reproduction issues and conflicts between household and larger institutions. Because of class and gender divisions of labor not everyone has direct access to economic means of survival. The capitalist mode exists because of ‘free’ labor. This seems to ring true in the case of care giving. Social relationships based on gender shape the organization of care (Graham, 1991). Marxist and socialist feminists would argue that caring can be seen as the unpaid work of kin within the private domain of the family. Women’s caring work, in the private sphere, is not recognized as work and policy effects on the family are not questioned and caring costs not considered. The retrenchment of the state is vehemently criticized. More recently, Neysmith (2000, p.4) talks about the “hollowing out” of the welfare state and argues that “if an ethic of care is translated into principles for guiding the development of policy, history will repeat itself and we will get a twenty-first century version of late nineteenth-century maternalism, which romanticizes domesticity” (p.4).

Although these different feminist approaches have very different views on who should be providing care, they share some key assumptions: None negate the importance of caring. Ultimately, they protest patriarchal structures, demand greater recognition of the importance of caring and more involvement in caring by men. They ask that women have a say in the allocation of public resources. It is imperative that we
challenge the division between the public domain (policy, medical establishment, labor market) and the private (family, care).

Against this background, we will now examine the recent academic and popular literature on care giving. Although, in the health and rehabilitative literature, research is mainly focused on the impact of care giving on health outcomes of the person being cared for, there is also some focus on the caregiver. This literature illustrates the taken-for-granted assumptions about family and women, demonstrates the lack of awareness of the feminist perspective on care giving and represents an interesting profile of a caregiver.

Care Giving as Ascribed Role

Care giving is frequently described (in both academic and in popular literature) in terms of the role concept. A number of research studies have looked specifically at care giving as a role. Baikie (2002) found that people caring for spouses with dementia commonly identify with the role of caregiver rather than that of spouse. Hogan and others, in a qualitative study of role changes experienced by family caregivers of adults with Alzheimer’s disease, conclude that caregivers experience significant life-altering role changes as a result of care giving responsibilities (2003).

Mittelman and others (2002) describe the ‘Spouse Care Giving Intervention Study’ at New York University, aimed at providing health care professionals advice on how to counsel Alzheimer’s Caregivers. They ask, with reference to family caregivers, how is care giving like a career?

Levine describes the transition after her husband’s brain injury as taking on a role ‘without informed consent’. She adds, “During my nine-year odyssey, I stopped being a wife and became a family care giver. In the anxious weeks when my husband was in the intensive care unit, I was still a wife.” She describes how she gradually became invisible—becoming a manager rather than a wife, being treated differently by the medical community, after the initial period when she was treated with concern. “In retrospect, I date my rite of passage into the role of family care giver to the first day of my husband’s stay in a rehabilitation facility… a boot camp for care givers” (2000, p.75). She argues that this demanding intensive kind of care should be a social responsibility, but that widely held concepts of family responsibility derived from religious teachings, cultural traditions, community expectations, emotional bonds, or gratitude for past acts inhibit family members from demanding this reconceptualization.

Degeneffe, in a thorough overview of research findings on family care giving and traumatic brain injury aimed to assist social workers in reducing demands of family care giving and improving caregivers’ quality of life, talk about the “assumption of a caregiver role” (2001, p.257). Jacobs (2000) states:
As numerous commentators in the field of families and health have pointed out, it is the meanings that family members attribute to a loved one’s disability that greatly shape their emotional reactions to providing care for that person. Those meanings arise from a host of sources, such as the nexus of relationships that have existed over time between the patient and his family members, the family’s tradition of caring (or not caring) for debilitated members and the cultural and religious values that guide the family’s notions of appropriate behaviors. (p.84)

Thus care giving is described as a demanding new role, which caregivers were not prepared for, lacking in clear role expectations. The new role frequently becomes a master status, as described above and acceptance of this role is prompted by their (culturally defined) view of family, responsibility and care.

Role Demands & Burden

The time involved in care of the disabled varies across the spectrum. Care giving can involve daily care and interaction, or it can mean advocacy for medical services on behalf of a relative. Estimates are that care giving activities add about an extra work week to women’s monthly load (Gerstel & McGonagle, 2002). We know that 17% of caregivers provide 40 hours of care a week or more (National Family Caregivers Association, 2007). But we also know that role expectations are increasing. The concept ‘caregiver burden’ which is frequently used in the literature, is a slightly different way of describing role demands. Many researchers have looked at stress and burden experienced by caregivers (Degeneffe, 2001; Ergh et al., 2003; Gan & Schuller, 2002; Heru, 2004; Lowenstein & Gilbar, 2000; Nabors, 2002). In summary, the caregiver role is consistently described and shown to be a demanding role, which does not lighten over time. Although a variety of factors can impact the experience of caregiver burden, it is repeatedly shown that caregiver needs and social support play an important role. Remarkably, this discussion is not contextualized in terms of the gendered nature of the role.

Health Effects

In a book with advice for caregivers Jacobs says, “[y]ears of selflessly lifting, spoon-feeding, toileting and comforting can cause caregivers to lose heart, burn out and break down. Once that occurs, their ability to care for their loved ones is undermined. Sheer exhaustion of energy and spirit may also place caregivers at risk for developing health problems of their own” (Jacobs, 2000, p. 84).

Care giving seems to be detrimental to the health of caregivers. Larkin reports that the overwhelming majority of caregivers neglect their
medical and other needs, both during care giving and after their relative dies, suggesting that intervention is needed to ensure that caregivers access services and take care of themselves (2001). Suthers reports that caregivers are more likely to have high blood pressure, elevated insulin levels, weak immune systems and cardiovascular disease. Of caregivers over 65, 63% have a greater mortality risk than their non-care giving peers (2006). Miller found a small but statistically significant difference in health strain between husbands and wives providing care giving, with wives experiencing more strain (1990).

Thus it is accepted that care giving can negatively impact the health of caregivers. This is typically framed within a financial context (as seems to be the focus of discussion around health care), and from the perspective of the needs of the person being cared for (if the caregiver is not healthy, she cannot provide good care!). Yet, physical health is only one part of the picture since mental health is also at stake.

**Depression & Anxiety**

A review of the literature tells us that caregivers can have significant psychological and psychosocial problems (Gan & Schuller, 2002). Caregivers experience twice the depression rate of the general population and depression is greatest for those taking care of cognitively impaired relatives (Crawford & Unger, 2004). We also know that depression and loneliness due to people having lost their social networks persist for years after the death of a care receiver (Larkin, 2001). Nelms et al. (2003), in an Australian study, found that anxiety and depression in families is higher among those who care for an injured (traumatic brain injury, or TBI) relative and that cognitive, behavioral and emotional changes are the strongest predictors of anxiety and depression. They conclude, “Every attempt should be made to develop models of long-term support and care that alleviate these sources of burden on relatives” (p.453).

There is ample evidence that women in general report more psychological distress than men. This is commonly related to gender socialization and to differentiation of roles. We know that women report more emotional distress in a variety of situations, not just care giving (Miller, 1990). This is ascribed to the fact that women are seen to have stronger affiliative orientations, they are perceived as more sensitive in relationships and more likely to use social support groups. Women are in general more involved in care giving activities and have less access to other informal and formal supports than men. This, the literature says, could lead to women experiencing greater strains as caregivers. Clearly this suggests that there is a systemic problem, but notably absent in the discussions is a critical awareness of hidden assumptions regarding women’s roles in society.

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2 This notion relates to the school of feminism that sees women as more nurturing, for example, see the work of Gilligan, 1982; Robb, 2006.
Social Support

The importance of social support for family caregivers has been firmly established. Social support includes aid in areas of care giving responsibilities, empathy, information and advice and can come from friends and relatives, support groups, or professional services. Social support can be either from informal social networks or professional services (Degeneffe, 2001).

Primary caregivers of people with TBI face isolation from friends and family, especially where the person cared for has behavioral problems. In this case support groups become important (Degeneffe, 2001). In addition, caregivers of the severely disabled have high supervisory burdens, have less access to social support and less time to seek out and engage in supportive contexts, so that they become further isolated and are thus less satisfied with life (Ergh et al., 2003).

The importance of social support for caregivers is without question. This suggests a need for bridging the gap between private and public worlds.

Marital Relationship

The research literature suggests that marital relationships can be impacted in a number of different ways. If a husband or wife takes care of a child or elderly relative, this can have an effect on the marriage. Clearly, also, if the person receiving care is a marital partner, the relationship has been altered.

In a study that looked at marital relationships of daughter caregivers, Suitor and Pillemer (1994) found that the quality of the relationship declined when the husband was unsupportive or interfered in care giving. They found (not surprisingly) that husband’s support was low when he perceived care giving as interfering with the wife’s traditional roles.

In the case of head injury of a spouse, the reciprocity of the marital relationship is affected (Miller, 1990). Eriksson et al. (2005) studied happiness in couples after brain injury and found that only 16 of 55 couples (29%) were satisfied with life as a whole and that joint experience of satisfaction was significantly related to the couple’s functioning in everyday life, particularly in leisure time and social life. The authors conclude that greater inclusion of partners in rehabilitation is necessary. However, it should again be noted that the focus is on the welfare of the person with the disability.

De Vugt and others (2003) found care-giver apathy in marriage where one has dementia with resulting decrease in communication. One study explored problem responses of caregivers to their care-receivers—such as feelings of resentment or hostility. Predictors of anger and resentment include a restricted social life, many patient behavioral problems, a high level of burden and emotional liability of the care-receiver. (Croog et
The importance of behavioral problems and emotional lability is supported by the frequency with which these issues are raised by caregivers who participate in online discussions. In fact, an analysis of message boards of www.tbihome.org seems to indicate that one of the most troubling factors with TBI care-receivers is that they become insolent and abusive to the caregivers—especially in the case of spouses. Posts also indicate that husbands with TBI expect a lot from their caregiver spouses—verbal and physical abuse are big problems.3

Discussions center on strategies to help women ‘deal’ with or ‘cope’ with this problem. In her book, Where is the Mango Princess? A Journey back from Brain Injury, Crimmins (2000) tells the story of her husband’s rehabilitation—in a particularly desperate moment, someone reminds her that she married him for ‘better or for worse’ and that she is now dealing with the ‘worse’ part of that deal. The complexity of a loving care giving relationship, coupled with societal expectations, inhibit any critique of a system in which care is relegated to family members, mostly women.

The expectations that the marital relationship is private has implications for the willingness of spouses to seek help. Burack-Weiss did a content analysis of published memoirs of people caring for the disabled. She says, “[g]oing public with a private matter marks a point of no return” (2006, p.65). According to her, this may be the reason why many spouses do most of the tasks themselves. She concludes that unless the health situation of the disabled person is self-evident, deciding what others have to know and when they have to know it is a major concern for young and middle-aged couples. People don’t know which friends they can rely on and which friends will turn away. In all the memoirs she investigated, regardless of the age or situation of the couple, they are treated by the world as a unit. Attitudes toward one invariably affect the other. This can contribute to social isolation. The private trumps the public.

CONCLUSIONS

In conclusion, home care giving is described as a taken-for-granted, unpaid role and assumed to be taken on willingly. It is a demanding role which can become a master status and it has financial implications for caregivers. It can negatively impact health and psychological well-being. This profile is eerily reminiscent of what Friedan (1963), half a century ago, with reference to housewives, called ‘the problem with no name’. We also know that care giving impacts marriage and family relationships and that caregivers do better if they have social support and coping skills. It makes them better caregivers, but also empowers them as individuals and improves their quality of life. Caregivers are not only the bridge between the private world of the family and the medical and rehabilitative estab-

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3 The message board of this group was monitored from September to December 2006.
lishments, they also do better if they themselves are more firmly rooted in social networks outside the immediate family. This suggests that the private/public divide is relevant on a number of levels. A review of the literature reveals, however, little or no recognition of the gendered implications of these facts. The way in which caregivers are portrayed, is a social justice issue. Clearly the feminist debate around policy related to care is crucial, but also needs to be disseminated much more widely than is the case at present.

The need for care of disabled will keep increasing, with changing demographics, continued war and higher trauma survival rates. In this paper a profile of the caregiver as reflected in research on caregivers was discussed in light of its gendered nature. Women are held captive by family ideology and the taken-for-grantedness of the caregiver role. The main purpose of the paper was to review and situate the research on care giving within this context. Nevertheless a few preliminary recommendations can be made:

Whatever our feminist points of departure may be (relational, liberal or Marxist/socialist), we have to challenge the ideology of care giving as being the domain of women. We also have to keep challenging the profit-driven nature of medical care, which benefits from this ideology. We have to create gender awareness in the professional medical community and reinforce it in the rehabilitative community. We have to find mechanisms to provide women caregivers with choices, without feeling that they are betraying their loved ones and men have to become more involved with care work. Finally, we have to challenge the notion that care giving is the responsibility of the private (family) and insist on the public (state) taking greater responsibility.

In the early nineteenth century, the French socialist Charles Fourier suggested that the level of development of a society should be measured by its treatment of women. Almost two hundred years later, according to Folbre and Himmelweit (2000), women themselves are insisting that social progress should also be measured by the quality of care provided for children and other dependents. It is clear that the current position of caregivers does not reflect adequate progress in either of these spheres. True social progress will be evident when society takes full responsibility for both those in need of care AND those providing the care.
REFERENCES


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