

BETWEEN A ROCK AND A HARD PLACE

THE MORAL DILEMMAS OF INFORMAL CAREGIVING

Allison M. Whelan

Ashley is an eleven-year-old girl who lives with her mother, father, and two younger siblings in Seattle, Washington.¹ She is not, however, a typical eleven-year-old who will soon experience the major developmental changes associated with puberty. On the contrary, Ashley will never grow up. Ashley's mother had a normal pregnancy and birth, but when Ashley failed to develop normal mental and motor faculties, it was clear that something was wrong. There is no known cause for her condition, which doctors refer to as "static encephalopathy of unknown etiology." This complicated terminology indicates that she suffers from brain damage of unknown origin or cause. The condition is not known to be treatable or reversible. Ashley is unable to hold her head up, roll, change her position, sit up on her own, walk, or talk. She must be tube fed and is dependent on others for her every need.

Not only does Ashley lack the mental and physical capabilities of an average eleven-year-old, she has also undergone medical procedures to permanently stunt her growth and maturation. Her body has been surgically altered to ensure that she does not grow much beyond her current four feet, five inches and seventy-five pounds. In 2004, Ashley's parents and doctors at Seattle's Children's Hospital formulated the "Ashley Treatment." The Ashley Treatment included estrogen therapy to close growth plates and stunt her growth; a hysterectomy to eliminate menstruation and the possibility of pregnancy; and breast bud removal to eliminate the discomfort of large breasts and reduce the risk of breast cancer (of which there is a family history). Ashley's appendix was also removed to eliminate the possibility of appendicitis.

A reasonable person would ask, "Why would Ashley's parents subject her to such procedures?" On their Web site, the "Ashley Blog,"

her parents repeatedly assert that the primary reason for the procedure was to improve Ashley's quality of life and *not* to convenience themselves as her primary caregivers. The hope was that the treatments would improve Ashley's quality of life by addressing her biggest challenges: "discomfort and boredom." Her parents offer a number of reasons for the treatment, including: (1) decreasing her size will make it easier for her caregivers to move her and take her places, increasing her mobility and ability to take part in activities outside of the home; (2) allowing her to remain cared for at home; (3) preventing sexual maturation to eliminate the discomforts of puberty, regular menstruation, and the possibility of pregnancy if sexually abused by a caregiver; (4) removing her breast buds to decrease the likelihood that she will be sexualized by a caregiver (which could lead to sexual abuse); (5) removing her uterus and breast buds to decrease the risk of cancer; (6) removing her appendix to eliminate the risk of appendicitis, which Ashley would be unable to communicate; and (7) keeping her small to make her round-the-clock care easier to manage. Her parents have nicknamed her their "Pillow Angel" because "she is so sweet and stays right where we place her—usually on a pillow" (Ashley Blog). Based on these justifications, it seems that the Ashley Treatment reduces the risk of almost any health condition Ashley could face in the future.

It is easy to perceive Ashley's parents and doctors as monsters, as individuals who have further disabled a child through invasive and potentially dangerous medical procedures. Many have questioned the best-interest argument used by her parents and doctors. I myself was at first appalled and shocked that her parents subjected Ashley to such procedures. But even if we do not agree with what was done to Ashley, we have to ask ourselves, Who are we to blame? Do we vilify her doctors, who we feel should know better than to perform such drastic procedures on a non-consenting individual and who should abide by the maxim "do no harm"? Do we criticize her parents, who should never intentionally harm or disable their children? Can we assume the procedures were done, in part, to ease the burdens they face as caregivers? It is much easier to blame the individuals directly responsible for these actions than it is to turn the blame around on ourselves, the collective society who can, and should, be at least partially responsible for the decisions made by Ashley's parents and health care providers. As Arthur Caplan (2007) stated about this situation, it was a "pharmacological solution for a social

failure.” Regardless of the decisions informal caregivers make, our inadequate social support systems present caregivers with a moral residue dilemma that lacks a satisfactory outcome. Caregivers are left to make the best *worst* choices, which frequently result in moral regret.²

This paper analyzes the moral dilemmas encountered by informal caregivers and makes suggestions for how these burdens can be eased. It first discusses the moral dilemmas and resulting moral regrets experienced by caregivers, providing some examples of the burdens experienced by caregivers in today’s society. It then analyzes some of the options currently available to caregivers and discusses how these options result in moral regret. The final section makes some preliminary suggestions for changes that can be made to improve the lives of caregivers and their dependents. These suggestions are based on existing systems that have been successful in other countries. This paper argues that the options currently available to informal caregivers in our society create a moral residue dilemma for the caregiver that ought to be, and can be, ameliorated through the rearrangement of societal priorities and institutions.

Moral Regret: The Burden of Informal Caregiving

Moral regret results from a moral dilemma in which one is forced to make an impossible choice that one cannot morally live with. None of the options available to the individual are acceptable, but it would be even worse to make no choice at all. A classic example of moral regret is the tragic choice faced by Sophie in the novel *Sophie’s Choice* (Styron, 1979). Sophie, a Polish, non-Jewish survivor of Auschwitz, was forced to make such an unbearable choice when she arrived at the concentration camp. She was forced to choose which of her two children (one boy and one girl) would die and which would live. If she chose neither, both would die. Sophie chose to sacrifice her eleven-year-old daughter, Eva, and was left with a guilt she could not overcome. This choice results in deep depression and self-destructive behaviors, ultimately resulting in her suicide. The term *Sophie’s Choice* symbolizes a decision that will result in moral regret. Neither choice was morally acceptable, but it would have been even worse if Sophie had not made a choice, allowing both her children to die.

There are four components to a moral dilemma: (1) the choice made and action taken by the individual results in feelings of regret or guilt; (2) these emotions are appropriate; (3) had the individual chosen the conflicting/opposing course of action, she would still feel regret or guilt; (4) if the conflicting course of action had been taken, the ensuing emotions would be appropriate (McConnell 1996, 37–38).

In our society, informal caregivers encounter moral dilemmas. They are forced to make choices about the care of their dependents in which none of the available options are completely satisfactory. Along with physical and emotional exhaustion, they are left with feelings of guilt and regret. If they choose to care for the dependent on their own, they regret what they have personally lost (their career, freedom, independent living situation, monetary savings); they regret the quality of care they feel they are able to provide the dependent because they feel they can never do enough to improve the dependent's quality of life; they regret neglecting other responsibilities; and they regret their feelings toward the dependent. Due to the burdens of caregiving, some caregivers feel resentment, anger, or wish that the dependent would die in order to end the dependent's pain and the caregiver's burden. These feelings provoke guilt, even though such emotions are common for a caregiver to experience (Williamson et al. 2005).

As a society, we have a tendency to praise or blame informal caregivers for events that are partially, if not wholly, due to bad brute luck.³ In most circumstances, individuals have little control over the situations that result in a dependent's need for care. Ashley's parents did not "deserve" nor ask for a child with profound disabilities, nor did they "deserve" to be members of a society that devalues caregivers and provides them with little, if any, support. Ashley's mother likely lived a similar lifestyle as other expectant mothers during her pregnancy with Ashley, yet she gave birth to an infant with profound disabilities while other women gave birth to healthy infants who would live "typical," healthy lives free of disability. Many conditions that place individuals in a dependent state are a result of chance: genetics, freak accidents, or rare illnesses are largely out of our control but can have a tremendous impact on our lives. The burdens of caregiving and the decisions made by caregivers are a result of brute luck but are nevertheless judged by others in society. If the caregiver is lucky enough to have

the resources to provide high-quality care in her own home, she is praised, but if she lacks the financial means and the emotional support to provide the level of needed care, she is blamed for failing at a task that should be “natural” and is blamed for harming the dependent whom she cares for. Caregivers have bad brute luck, which results in the situations that lead the caregivers to experience moral regret.

If the caregiver’s situation is a result of brute luck, is it appropriate to make moral judgments about the decisions she makes? If we agree with the concept of moral luck, we may believe it is appropriate to judge her actions. Moral luck can be defined as occurring “when an agent can be correctly treated as an object of moral judgment, despite the fact that a significant aspect of what he is assessed for depends on factors beyond his control” (Nelkin 2008). If we disagree with this idea, we can use the “Control Principle” as a guide to our judgments: the Control Principle asserts that moral judgment should only be applied in situations where individuals had freedom in their actions and *only* to the extent that they were able to determine the outcome. For example, if the person who just stepped on your toes was pushed by someone, your temptation to blame him may disappear because stepping on your toes was not his intent nor was it in his control. There are many circumstances, however, in which the objects of our moral assessment do appear to depend on circumstances beyond the agent’s control: we blame those who *actually* commit a murder more than we blame those who have merely *attempted* murder, even if the only reason for this failure was because the intended victim unexpectedly tripped and fell just as the bullet whizzed over his head. Neither murderer had control over whether the victim tripped, but nevertheless we judge (and punish) the murderer and the murder attempter differently based on a factor not within their control (Williams 1993; Nagel 1993). Is it appropriate to morally assess caregivers for decisions they must make when faced with a situation that is not under their control? The situations informal caregivers face are largely due to chance; they simply happen to be in a position that renders them most likely and most able to provide the needed care. Because these circumstances are a result of brute luck, it is inappropriate to vilify caregivers and condemn their actions as immoral. On the contrary, we must provide support and assistance to rectify their disadvantaged positions that resulted from bad brute luck.

Ashley's parents are informal caregivers, those who are there because no one else is, because they cannot afford full-time professional assistance, or because they view it as their responsibility to ensure their dependent's intensive and continuous needs are met. An informal caregiver's work is neither recognized by the labor market nor is it monetarily compensated. Informal caregivers often take on the role because they view it as a duty, a responsibility, and because if they do not do it, no one else will.

In our society, caregivers face multiple burdens: the burden of caring for a loved one who is in a dependent condition (profoundly disabled, Alzheimer's, terminal cancer, etc.); the burden caused by the lack of available support; and the burden of being criticized for not making the "right" decisions. Informal caregivers are given the responsibility to care for a dependent and are expected to be perfect caretakers with little, if any, outside support. These burdens are not mutually exclusive, they are all related, and an increased burden in one may increase the burden in another.

Caring for a dependent loved one can be rewarding and personally fulfilling, but it also comes with many burdens and stressors. Not only can it be difficult to see a loved one in a dependent state, in pain, losing his memory, or dying, the work of caregiving itself is also mentally, emotionally, and physically exhausting. These burdens are largely placed on women—it is estimated that between 59 and 75 percent of informal caregivers are females. The average caregiver is a forty-six-year-old married woman, most of whom do not or cannot abandon one responsibility (such as their job) for another (caregiving) but rather try to cope and make do with the extra responsibilities (Arno, Levine, and Memmot 1999; Pavalko and Artis 1997). As a result of the stress, exhaustion, and physically laborious work of caregiving, many of these women end up needing care themselves—higher levels of depression, anxiety, and mental health challenges are common among female caregivers. Caregivers have a tendency to neglect their own health in order to provide care for the dependent: many have high blood pressure and high cholesterol, addiction problems, depressive symptoms, and other chronic illnesses but ignore these issues because of their busy and burdensome schedules (Family Caregiver Alliance 2009). Increasing numbers of men are taking on caregiving roles in recent years, but women still disproportionately take on the caregiving role and face the tremendous burdens on their own.

A lack of social support exacerbates the burdens of caregiving. The current policies and institutions in place are inadequate and do not meet the needs of caregivers and their dependents. The worth of the services provided by informal caregivers in the United States is estimated at more than \$257 billion annually, more than twice the amount spent on paid home care and nursing home services combined (Suthers 2006). Yet these caregivers receive little, if any, support from society. Kittay (1995) argues that the United States is “especially primitive in its response to the concerns of dependency work” and the passage of the Family and Medical Leave Act⁴ in 1993 illustrates the inadequate support for caregivers,⁵ who are frequently left to their own devices to provide care for their dependent, maintain a job, and take care of other familial and workplace responsibilities that they are unable to give up to become a caregiver. The high value our society places on individualism has resulted in a system that abandons those in need. Our society has applied an autonomy model to a situation needing a collective action solution.

Informal caregivers also face social condemnation. In the eyes of an outsider, an informal caregiver may never be good enough. If a woman quits her job to become a primary caregiver she is condemned by some for succumbing to traditional gender roles; if she chooses not to provide care and places the dependent in an institution, she is criticized for her selfishness and failure to take responsibility for the dependent’s care. It is a losing battle, and there is never a solution to satisfy everyone in society, let alone the caregiver herself. Those who accept the responsibility of caregiving (regardless of whether they give up or maintain other roles of responsibility) face the societal devaluation of caregiving and the negative connotations that go along with dependency and dependency work: “[D]ependency...is the dirtiest word in the United States today” (Solinger 2002, 61). Dependency is now most frequently associated with “welfare dependence” and is a condition that is racialized, feminized, and pathologized (Solinger 2002). Our society’s devaluation of caregiving and condemnation of dependency decrease our willingness to provide assistance to informal caregivers to lessen their burdens.

Before going farther, it is important to clarify the distinction between a burden and a moral dilemma—they are not interchangeable terms. A burden can be formally defined as “something oppressive or worrisome,” whereas a dilemma can be defined as a

“predicament” or “argument presenting two or more equally conclusive alternatives against an opponent” (“Burden”; “Dilemma”). All of us, at some point in our lives, are burdened by something or someone. Not all burdens are of the same weight. Life is full of burdens and not all burdens are “unfair.” A job can at times be a burden; being a college student comes with the burdens of essays to write, exams to take, and newfound “adult” responsibilities to take care of; raising children can be burdensome, and so on. This paper, however, is most concerned with the unfair imposition of burdens that lead to a moral dilemma. Moral dilemmas are those situations in which an individual is left with a moral residue no matter what she chooses to do. This is not always the case with burdens—there can be, and often is, a “better” course of action to take when faced with a particular burden. Moral dilemmas, on the other hand, are a special kind of burden, and ones that only particular individuals get saddled with in their lives. Burdens are not necessarily moral dilemmas, but moral dilemmas are always accompanied by burdens. The moral dilemma occurs when an individual attempts to alleviate her burdens through a particular course of action but realizes that no matter what decision she makes, there will still be residual guilt and dissatisfaction with the particular decision that is made.

Caregivers fight a losing battle: there is no completely satisfactory outcome for the situation they are in, but decisions must be made to prevent the burden from becoming impossible to handle. Given the burdens they face and the need to reduce these burdens, what options do caregivers have?

The Extreme: The Ashley Treatment

One option is to take the course of action followed by Ashley’s parents—a “drastic times call for drastic measures” approach. Given the difficulties of caring for someone with the severity of Ashley’s disability, her parents felt they needed to do something to make her care less burdensome and to improve her quality of life. Our society’s lack of support for caregivers may be a major reason why Ashley’s parents believed the Ashley Treatment was not only acceptable, but also in Ashley’s best interest. Society frequently blames the caregiver for the outcome of her decisions, even though societal structures/institutions are partially, if not wholly, responsible for the fact that such a choice had to be made in the first place.

If Ashley had grown to the size of a mature adult, her care would have undoubtedly been more difficult. With age, her parents may have found it difficult to lift and carry Ashley, which limits her mobility and ability to leave her house and experience the world outside of her bedroom. Monthly menstruation could indeed have been a burden for both Ashley (who would not understand what was happening to her body) and for the caregivers responsible for her hygiene. It is very unfortunate, but there is some truth to her parents' worries about the risk of sexual abuse and/or exploitation by caregivers in the future if/when her parents are unable to care for her. According to one study, more than 90 percent of people with developmental disabilities will experience sexual abuse at some point in their lives and 49 percent will experience ten or more incidences of abuse (Valenti-Hein and Schwartz 1995). While these facts alone do not justify her parents' decision, it does raise questions about how our society views and treats disabled individuals. We should not have to subject an individual to invasive and irreversible medical procedures to decrease the risk of sexual abuse. We should not place responsibility for such abuse on the victims by claiming it is their bodies that incite the abuse. It is not the victim that needs to change; it is the perpetrator. The fact that Ashley's parents felt they needed to take such measures to lessen the chance of abuse sends a terrible message about our society's treatment of the disabled.

Regardless of the choice made by the caregivers, the result is not completely satisfactory. Choosing to do the treatment subjected Ashley to invasive, irreversible, and ethically questionable medical procedures that may not have been in Ashley's best interest. It brought about much criticism from outsiders and created the potential for the caregivers' guilt and regret for consenting to such procedures simply because they felt they had no other option. Opting not to do the procedures could have resulted in a lower quality of life for Ashley and the inability for her to be cared for by those who truly love her—her parents. Caregivers who opt for the medical procedures will face criticism, accusations of child abuse, and their own guilt and regret for subjecting the dependent to procedures the individual cannot consent to; caregivers who choose *not* to use medical interventions may feel guilty for being unable to provide the high level of necessary care (possibly resulting in institutionalization) and may be viewed by society as failures.

Is this option justifiable? Should we allow such procedures to ease the burdens of caregiving? Should we allow caregivers to have the right to make decisions on the basis that such decisions will make caregiving more “convenient,” even if the outcome is not necessarily in the best interest of the dependent? Do we sacrifice the care receiver’s right to always be treated with dignity and respect,⁶ in a manner that recognizes her rights as a human being, no matter how disabled she is? Do we increase the caregiver’s ability to act autonomously and in her own best interest at the expense of the care receiver’s best interest? Regardless of the justifications given for the procedures, if caring for a full-grown disabled woman were less burdensome, some (if not all) of the procedures would have been unnecessary.

Procedures such as the Ashley Treatment are not justifiable options because they are far too drastic. Ashley’s case is extreme, but her parents and even some doctors are suggesting that this should be an option available to the parents of other “pillow angels” (The Ashley Blog 2010; Diekema and Fost 2010). These medical procedures should not become necessary or acceptable in order to ease caregiving burdens in our society. It can certainly be argued that because of the reality of limited resources and because the resources needed for the care of individuals such as Ashley are not available, this option may make sense and her parents may be “taking the only option open to them” (Liao, Savulescu, Sheehan 2007, 19). However, there are too many dangerous implications for this to be a valid option.

A caregiver’s right to exercise her own autonomy does not extend to a right to infringe on the individuality and dignity of the care receiver. Some supporters of the Ashley Treatment argue that because Ashley does not have the ability to feel and experience indignity, then treating her with dignity is not of primary importance. As George Dvorsky (2006), a member of the board of directors for the Institute for Ethics and Emerging Technologies claimed:

If the concern has something to do with the girl’s dignity being violated, then I have to protest by arguing that the girl lacks the cognitive capacity to experience any sense of indignity. Nor do I believe this is somehow demeaning or undignified to humanity in general; the treatments will endow her with a body that more closely matches her cognitive state—both in terms of her physical size and bodily functioning.

The estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby.

Simply because individuals with severe disabilities cannot understand or recognize dignity and do not know what it means to be dignified or undignified does not grant us the right to treat them in any way that we please.⁷ They may not know what it means to be human, to be a person, and to be alive, but this does not give us an excuse to treat them inhumanely or with disrespect. If a person cannot feel pain, does this give us the right to punch them? Does this give us the right to stab them? No, it does not, and unless we are willing to admit that disabled individuals are not “persons” in the same sense as you and I, we cannot justify treating a disabled individual with less respect than any other person.

If we are disturbed by the abuse of vulnerable and disabled individuals, we clearly cannot allow the Ashley Treatment to become a valid option for caregivers. We could place legal limits on how far caregivers could take such treatments, but the Ashley Treatment makes it clear that we have already allowed it to go quite far. By justifying their actions as being in the best interest of the dependent, these procedures could easily be abused by caregivers who wish to convenience themselves. The argument can be made that the less burdened the caregiver feels, the lower the caregiver’s stress, and the better her care of the dependent will be. Far too much could be, and already has been, justified under the guise of “benevolence” and “good intentions” toward the disabled community, often with disastrous consequences: “Throughout history, ‘for their own good’ has motivated and justified discrimination against [the disabled community]” (Disability Rights Education and Defense Fund 2007). Can fundamentally changing who a person is truly be in one’s best interest? Ashley may not be able to express who she is or how she experiences her identity, but the Ashley Treatment eliminated her gender and her ability to grow and mature. Ashley’s parents promote this treatment as an acceptable technique to help other “pillow angels” but the good intentions of her parents could indeed spell disaster for the broader disability community. How far would this go? If Ashley’s case is any indication, allowing the Ashley Treatment to be an available option would be too extreme and have dangerous implications for the future treatment of the disabled.

The more one learns about Ashley's situation and the lack of resources available to her family, the more difficult it becomes to condemn her parents and doctors. If we can acknowledge that these treatments may have been in Ashley's best interest, the only reason for this is because of our inadequate system of social assistance and the way our society views the disabled. We devalue the disabled and do not provide for them in a way that makes their care anything but extremely burdensome. All disabilities are at least partially socially constructed and the resulting burdens faced by caregivers are a consequence of this construction and lack of resources allocated to the care of individuals in need. While some disabilities are disabilities in and of themselves and thus unable to be completely eradicated through changing social structures, the extent to which these disabilities cause burdens *could* be lessened. This is one reason why expanding the use of the Ashley Treatment is so problematic and difficult to grapple with because it seems such drastic measures would not be required if we could change our society. This is why the Ashley Treatment is so ethically problematic: *it did not have to come to this*.

We all know that it did not, and should not, have come to such extremes, and this is why we try to place the blame on her parents and her doctors. It is easier to blame others than to try to change our society, our values, and our incessant individualistic tendencies that prevent us from constructing a collectivist solution to help with the care of those who are dependent.

Accept the Status Quo

Another option is to do what the majority of caregivers currently do: accept the status quo and try to get by with the system set up as it is. Caregivers may decide to provide their own care, make use of the professional care they are able to afford, make the dependent a ward of the state, or institutionalize the individual in need of care.

Choosing to take on all caregiving responsibilities (or with limited professional help) is an immense and complex decision to make. When the dependent is a loved one, some may *want* to provide the care and/or feel it is their duty to do so. "Dependency workers" are those who care for dependents (paid or unpaid) and who devote much of their time, energy, attention, care, and material resources to provide the needed care (Kittay 1998, 37). As previously discussed, caregivers accept a tremendous burden, and the fact

that the dependent is a loved one does not ease this burden. Even if professional assistance can be afforded, the professional cannot be present twenty-four hours a day, seven days a week, and thus the informal caregiver is left with a significant portion of the caregiving duties, along with any other responsibilities in her life.

Many informal caregivers do get satisfaction from caregiving but this satisfaction may come paired with regrets. They must make many sacrifices—personal, professional, financial, and emotional. Some have to give up their careers or decline promotions in order to provide care for the dependent. Most caregivers willingly take on dependency work and we certainly do have some level of responsibility to care for those in need. However, the “willingness” of caregivers is more likely a result of having limited alternatives. The “choice” to become a caregiver is not much of a choice at all and the decision to become a full-time, informal caregiver may be viewed as the best *worst* option rather than the ideal option because of the sacrifices entailed. Research has found that more than half of all informal caregivers spend 10 percent or more of their annual income on caregiving expenses, which suggests that the money they spend today on the dependent’s care is money they will not have to meet their own needs in the future. The costs of a home health aide will add up quickly. In New York, the average hourly rate for a home health aide is \$21. If the health aide provides just fifteen hours of assistance per week (much less than some informal caregivers realistically need) and works fifty weeks of the year, this care would cost almost \$16,000 (United States Department of Health and Human Services 2010). This would be in addition to all the other medical needs of the dependent, and there is no guarantee insurance will cover these expenses.

To meet a dependent’s needs, a caregiver may go into debt, sacrificing her own needs and those of the rest of her family. If a parent has three children, one of whom needs constant and expensive care that causes the family to go into debt, what does this mean for the other children? Will the parents be able to afford the basic health care needs of their other children? Will the children be able to go to college? Sacrificing the needs of one child for the sake of another can cause enormous feelings of guilt for the parents who have such an immense responsibility at the present (the care of the disabled child) that they cannot be concerned with the future of their other children. If the parent tries to remain fully attentive to the needs of

another child, this may decrease her ability to meet all of the disabled child's needs, which could negatively impact that child's quality of life. This is another situation in which there is no completely acceptable outcome — if the parents provide full attention to the disabled child, they sacrifice the needs and well-being of the “healthy” child, and if they divide their attention, the disabled child's quality of life may suffer.

Informal caregivers may also regret the quality of care they are able to provide. They may feel inadequate and unable to provide the level and amount of care needed. Certain disabilities and health conditions are so complicated that there is little that can be done to bring the dependent's quality of life to the level the caregiver desires. Caregivers often cannot take a break from their caregiving responsibilities (unless it is to take care of another responsibility such as their job or care of other family members) which can have a negative impact on their physical and psychological well-being and lead to burnout. Caregivers often feel guilty taking time off of their caregiving duties to meet their own needs, and they feel selfish for thinking of themselves (Spillers et al. 2008). Some conditions are so medically complicated that feelings of inadequacy and resulting guilt are not surprising. If complications with the dependent's condition arise, the caregiver may blame herself and feel that she failed her dependent. For some, the burden of caregiving and accompanying feelings of guilt can become overwhelming, leading to a deterioration of the caregiver's own health, ironically causing *her* to become dependent on others as well.

The status quo in our country is neither desirable nor acceptable. Our society's emphasis on individualism, failure to appreciate the work of caregivers, negative connotations of dependency, and disjointed social welfare system all burden the informal caregiver in such a way that she can never be satisfied with the care she provides and the sacrifices she has had to make. The burdens of dependency work are not being shared equally within the family and society. Even if we believe that *society* has no responsibility to assist caregivers, within the *family* there still exists an unequal distribution of caregiving responsibilities, most of which are given to women.

A greater focus has been placed on ensuring justice for the dependent (e.g., disability rights) than there has been on justice for the caregiver. However, both are important, and ensuring the just treatment of the care receiver does not necessarily result in

justice for the caregiver. Informal caregivers are being treated as a means to an end rather than an end in themselves, an unjust situation by Kantian standards (Kant 2008). As a society we have tried to improve the lives of the disabled, but we have forgotten about those who make their improved well-being possible—their caregivers. Any responsibility of society to assist in the care of the disabled and/or dependents has largely been shifted to informal caregivers: parents, grandparents, spouses, children, and friends. Intentionally or not, societal structures unjustly exploit informal caregivers—by making them feel as if they have a *duty* to care for the dependent, society avoids any sense of responsibility and avoids the redistribution of resources to provide for the well-being of the care receiver and the caregiver.

Institutionalization

Institutionalization of the dependent and/or making the dependent a ward of the state is another option that has been used. However, this is not an acceptable option for informal caregivers and their dependents. Institutions such as nursing homes and assisted living centers have made significant improvements in the quality of care provided, but it is often not an ideal living arrangement. For younger dependents, there is a lack of age-appropriate care facilities—should a twenty-six-year-old disabled woman have to live in a nursing home where the resident closest to her in age is forty years her senior? This type of living arrangement can be degrading, dehumanizing, and often results in declines in health, well-being, and abilities. Large institutions can have a “crippling effect,” resulting in declines in residents’ abilities to communicate and interact with others, foster dependence, and decrease residents’ motivation and ability to develop independent skills (Frolik 2008, 232). There is a history of abuse in institutions for the disabled, and institutionalization is associated with discrimination and stigma. The care provided by an institution may not be what the dependent needs and may in the long run do more harm than good:

Institutions beget hopelessness, helplessness, and abuse. Institutions cannot provide that measure of human service which society must demand of entities that purport to serve people. Whenever one group of people assumes power and authority over the lives

of individuals gathered into an institution, usually on the basis of characteristics devalued by society as a whole, and where professionals claim skill in management of these individuals, abuses of all kinds are inevitable. These institutions do not habilitate people. They harm people. They do not support growth; they undermine growth. These institutions do not build; they destroy. (Ferleger and Boyd 1979, 721–22)

If the informal caregiver feels institutionalization is the only way for the dependent to get the care he needs, the caregiver may feel tremendously guilty for being unable to provide the care on her own. It can be extremely difficult to institutionalize a loved one, especially if one is aware of the mistreatment and low-quality care that has occurred in some institutions. Even if they would like to care for the dependent and are willing to do so, for some this simply may not be an option. Most parents would not want to place their disabled child in an institution and will likely be criticized if they do. Others who do not understand the situation may harshly judge the parents—many believe that caring for one's child is a personal responsibility, a job that society expects everyone to be able to do. When unable to do so, such societal attitudes can cause caregivers to feel as if they failed at a role that should come naturally. Once again, caregivers face the unacceptable choice between caring for the dependent on their own or institutionalizing the dependent. If the dependent is institutionalized, the person responsible for the institutionalization (who would have otherwise been the caregiver) may feel guilty for placing the dependent in a facility away from friends and family; she may regret being unable to provide the care herself; she may fear the possible mistreatment of the dependent in the institution; and she may resent the critical judgment of others. Our societal systems have placed caregivers between a rock and a hard place—there is no completely acceptable choice to make and the caregivers will always be left with feelings of dissatisfaction and frustration.

What Now?

What *can* we do, if anything, to ease the burdens of informal caregiving? It is clear that something must be done. What this section

proposes is neither the best nor the only solution to this problem. As a society, we must stop ignoring the issue and end the perpetual “cycle of malignant neglect and obliviousness to the situation of the disabled” (O’Shea 2009, 22). Fortunately, as a result of the aging population and growing number of individuals requiring care, the problems faced by informal caregivers are increasingly being brought to the public’s attention. However, improved awareness has not been matched by improved support.

The first step we must take is to admit the existence of a dilemma. We must first realize that the way our society functions and the values we hold prevent us from providing the support that informal caregivers need. Our society makes disabilities more disabling than they have to be—many conditions we view as “disabilities” are socially constructed rather than innate. The social model of disability views disability as “a result of the environment in which an individual with a particular disorder operates with the ultimate effect of disabling his or her function in ‘normal’ activity” (O’Shea 2009, 22). Disability occurs because of “cultural, physical, or social barriers which prevent their access to the various systems of society that are available to other citizens” (Kaplan 2003). The barriers faced by the disabled are largely a result of societal attitudes and resources rather than actual abilities: “The problem is defined as a dominating attitude by professionals and others, inadequate support services when compared with society generally, as well as attitudinal, architectural, sensory, cognitive, and economic barriers, and the strong tendency for people to generalize about all persons with disabilities overlooking the large variations within the disability community” (*ibid.*).

Our neglect and obliviousness to the needs of the disabled make it extremely difficult for caregivers to obtain the resources needed for their dependents. Many have objected to the Ashley Treatment by claiming that disabilities, including Ashley’s, are socially constructed and should not have to be medically treated in the way Ashley was. However, the reality is that those who defend the Ashley Treatment are correct when they point out that the resources Ashley and her parents would have needed are far above and beyond those that are available at this time (Liao et al. 2007). The cost of long-term care and the limited resources available to caregivers can help us understand (but not necessarily agree with) the decisions made by Ashley’s parents—it was a cheaper and easier solution to perform

insurance-covered medical procedures than it would be to provide the long-term, more difficult care of Ashley as a full-grown woman.

We have gotten stuck in our inadequate system and have allowed the “what is” arguments to override what *ought* to be and what *can* be. There may not be a *best* answer but there are certainly *better* ways to support caregiving than the way our society does so currently. We cannot place the burden solely on the shoulders of the caregiver nor can we criticize the caregiver for being unable to provide all of the necessary care on her own. We must recognize, as suggested by Martha Albertson Fineman (2004), that the idea of autonomy is a myth and that “our particular way of thinking about the desirability and attainability of autonomy for individuals and families has seriously limited the ways in which we think about equality” (xiii). The American values of autonomy and respect for individual rights are in direct opposition to the reality of dependency that affects *all* of us at some point in our lives. Autonomy is a deeply ingrained value in American government and culture, which makes it difficult to advocate for better care of the disabled through greater social responsibility. Our respect for individualism has led to our disregard for those who are dependent and to the delegation of their care to those who feel they have no other option—family or close friends. We assume that everyone *can* be autonomous and self-sufficient and we stigmatize those who cannot develop these characteristics. The reality is that at some point in our lives, we will all be dependent on someone else—whether it is for a short or long period of time, it *will* happen. We deceive ourselves when we think that everyone is (or can be) autonomous, and we would all benefit from recognizing the deficiencies of our current model of society (Fineman 2004). This will certainly be an arduous process, because the idea of collective responsibility for dependency can be difficult to garner support for in a nation founded on the ideals of individual rights. While making a place for the rights of the individual, our society has unintentionally created an unjust system for those who are dependent on others for their survival.

We cannot necessarily eliminate the moral dilemmas faced by informal caregivers, but as Ruth Barcan Marcus (1980) argued, we can “stack the deck” so that these dilemmas do not arise or are lessened (130). We can arrange societal institutions in a way that prevents the previously described decisions from being the only feasible options. Other countries have found ways to stack the deck, suggesting that it is not impossible to arrange society in such a way as to

decrease the existence of moral dilemmas. According to Marcus, “As rational individuals with some control of our lives and institutions, we ought to conduct our lives and arrange our institutions so as to minimize predicaments of moral conflict” (121).

We can use systems found in other countries as models for how to rearrange American society to provide better support for caregivers. We must acknowledge that systems used in other countries cannot simply be transferred to the United States and implemented. Different population sizes, demographics, and values must be taken into account. However, using another country as a model can help us realize that changes *can* be made to improve the lives of caregivers and their dependents. To make these changes, we must reorganize and reprioritize some of our fundamental societal institutions.

The Canadian system of community care provides a suitable model to assist us in determining the path our society should take as well as which solutions could feasibly be implemented based on the differences between Canada and the United States. The Canadian system emphasizes home and community care, which are defined as “services to help people to receive care at home, rather than in a hospital or long-term care facility, and to live as independently as possible in the community” (Health Canada 2010). The model emphasizes the importance of support for the caregiver and seeks to balance the promotion of the care receiver’s independence while recognizing his areas of dependence and need for support. Canadian caregivers face less of a financial burden than their American counterparts due to higher levels of federal funding for long-term, home-based care. For nursing home care, all individuals contribute to the cost of their nursing home care, but how much they pay depends on their *ability* to pay. All provinces have mechanisms to ensure that people receive the care they need without leaving an enormous debt to the patient’s family (Stadnyk 2002). This is in contrast to the United States, where long-term care is often paid by the individual. Contrary to many people’s beliefs, Medicare only pays for short-term nursing home care. Those who qualify for Medicaid or certain other state-funded programs can obtain coverage in this manner, but many individuals have to pay a large portion, if not all, of their long-term care expenses out of their own personal income and assets (United States Department of Health and Human Services 2010). The Canadian federal government provides funding support to provincial, territorial, and some municipal governments to provide

home and community care services, enabling individuals to get the care and support they need without a tremendous financial burden. The community care model is an alternative and/or complement to informal caregiving. In contrast to the insurance-based system in the United States, Canadian health services are primarily paid for by the government and paid home care is used in tandem with informal care, providing needed care and easing the burden on informal caregivers (Health Canada 2010). The Canadian model is much more complicated than this description makes it appear and it certainly is not perfect, but its emphasis on community care is a model the United States should look toward to solve the issues faced by caregivers. As a society, Canadians have at least recognized and accepted that there is a dilemma, and their home and community care model is attempting to address the dilemma and ease the burdens of caregivers in their society.

To be clear, this paper is not arguing for a government “takeover” of the care of the disabled. As with any federally and state-funded program, there would have to be certain eligibility requirements and restrictions on what the funding could be used for, but in a system similar to the one this paper proposes, the government would not dictate the exact course of care for the individual. The government would not control all aspects of the care receiver’s care and would not be a legal guardian of the disabled. On the contrary, a community-based model is trying to avoid the situation in which the caregiver feels they have little choice but to turn the disabled over to the state and/or place the care receiver in an institution. The goal is to create a collaborative, community-based system—not a government takeover and “nanny state.” As demonstrated by the Canadian model, this paper argues for the creation of a community-based system of care provision that will act as a social safety net that is there for all individuals if/when they need it. Not all of us will face the moral dilemmas of caregiving, but many of us will. We could all be caregivers for a severely dependent individual at some point in our lives and most of us, if we live to old age, will be care receivers. Thus, the funding of a community-based caregiving system would not unjustly “benefit” some groups of individuals, because all of us are potential caregivers and/or care receivers (and it is justifiable to say that no one would desire to be in a situation requiring them to make use of the system—but if the need is there, the services should be there as well).

There are glimmers of hope in the United States that we are finally beginning to recognize the need for improved caregiving systems. In Georgia, for example, disabled individuals have access to a state and federal program that pays for aides to visit a disabled individual's home and provide care for a significant portion of the day, which enables the informal caregiver to maintain a job outside of the home (Shapiro 2010). Another program that many states have begun to implement is "Money Follows the Person," which assists states in balancing their long-term care systems and "reflects a growing consensus that long-term supports must be transformed from being institutionally-based and provider-driven to "person-centered," consumer directed and community based" (Department of Health and Human Services Centers for Medicare & Medicaid Services 2010). For example, this program allowed Matthew Harp, a twenty-two-year-old with a muscle disorder, to move back into his mother's home from a nursing home, by paying to renovate the home and making it more wheelchair-accessible for him (Shapiro 2010).

It is not well known, but disabled individuals do have a Supreme Court-affirmed right to remain cared for in their homes. In *Olmstead v. L.C.* (1999), the Supreme Court ruled against the state of Georgia, finding that "states are required to place persons with mental disabilities in community settings rather than institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities" (*Olmstead v. L.C.* 1999). The Supreme Court used the Americans with Disabilities Act to argue that it is a form of discrimination to unnecessarily institutionalize a disabled individual (Shapiro 2010). Since the *Olmstead* decision, federal policies say that states need to "do more" to meet their obligations and need to create more community-based care, but disability advocates claim there is an "institutional bias" in federal law that requires state payment for nursing homes, while payment for community-based care is optional (ibid.). Clearly, the recognition of a legal right to community-based care has not significantly improved the situation of the disabled. As this paper argues, however, there is more than a *legal* right to such care—the provision of community-based care is the ethically desirable thing for our society to do. Legal precedent makes clear that we

recognize that there is something valuable in community-based care and improved living situations for the disabled, but we have failed to put this recognition into meaningful action.

“It’s Not My Burden to Bear”

Regardless of the value we place on individual rights, if we find the previously discussed options for the care of dependents to be problematic, then we must look for a solution and better way to provide support for caregivers. The value many place on individual autonomy in our society will always pose a problem for ideas that are more collectivist in nature. The following argument will inevitably arise: “Why should the burden of the caregiver be shifted onto me and others in society who are so far removed from the situation? Why should I have to feel any of the burden?” The first response to this argument is that this statement recognizes the burden—by asserting your right to not have to bear a portion of the caregiver’s burden, you are accepting a major part of this paper’s thesis—that there *is* a burden and that there is a problem that needs to be addressed. Even the most extreme individualists must admit that at some point in their life, whether it was in childhood, sickness, or disability, they have been in a position in which their well-being was dependent on the care of someone else.

There are many possible responses to the individualism argument, all of which reach a similar conclusion: we need a collectivist solution to the dilemmas of informal caregiving. From the standpoint of distributive justice, we must restructure our society to distribute the benefits and burdens of informal caregiving in a manner that is more equitable and fair. From a virtue ethics perspective, it is simply the benevolent, moral, and virtuous thing to do. Care can be understood as a virtue, and, thus, supporting those who provide care is the ethical thing for society to do (Sander-Staudt 2006). A consequentialist could see greater societal responsibility for caregiving as an option that is best for all of us—we will all at some point in our lives, whether as caregivers or care receivers, benefit from an improved support system for caregivers. From a Kantian view, we need to restructure society so as to treat caregivers as ends in themselves rather than as a means to an end. The work of informal caregivers is currently exploited—they are a cheap (if not free) method of

care provision for dependents in our society. And care ethics would support the emphasis this solution puts on emotions, contexts, and the relationship of the caregiver and care receiver rather than on individualistic principles (Campbell 2010). All of these arguments can be used as support for this paper's conclusion that we need to change our societal systems and promote a caregiver-support policy that is collective rather than individualistic. Not only can each of these perspectives provide a response to the individualism argument, but they all support this paper's argument, providing evidence that its conclusions and suggestions are reasonable.

This paper argues that collective responsibility and a form of community care for dependents is a possible solution for the dilemmas of informal caregiving. We cannot sit back and place the blame on individuals such as Ashley's parents or her doctors who performed the procedure. Even if we completely disagree with the choices they made, we must acknowledge that there is a lack of acceptable options currently available to informal caregivers. We must recognize that Ashley's parents truly felt they were doing what was best for their daughter while living in a society that does not provide the support and resources needed for individuals like Ashley to have a decent and dignified life. We cannot vilify her parents unless we can truly say that as a society we are doing everything possible to ease the burdens of informal caregivers. Caregiving will never be easy, but it does not have to be as difficult as it currently is in our society. "If we as a society believe that it is undignified, as a matter of human rights, for Ashley to undergo these treatments, then we must be prepared to provide her caregivers with enough assistance and support that they would not have to resort to these means. Upholding human dignity comes with a price, and if it is what we should value as a society, then we must be prepared to pay to uphold it" (Liao et al. 2007, 19). The question we are left with is: Will we?

NOTES

1. The information about Ashley in this section was obtained from her parents' Web site, The Ashley Blog which can be found at <http://ashleytreatment.spaces.live.com/blog/>.
2. By moral residue dilemma, I am referring to "a situation in which an agent cannot avoid doing something that will justify some moral residue." Moral residue

includes moral guilt and moral regret, as well as “obligations to apologize, explain, or compensate after the act, or to seek release in advance” (Mason 1996, 54).

3. As defined by Peter Vallentyne (2002), “Brute luck as (reasonable) unavoidability: the occurrence of an event is due to brute luck for an agent if and only if the agent could not have (reasonably) avoided the possibility of its occurrence” (532).
4. According to the U.S. Department of Labor (2010) Web site, the FMLA entitles eligible employees to twelve workweeks in a twelve month period for the birth and care of a child within one year of birth; adoption/foster of a child; care for employee’s spouse, child, or parent with a serious health condition; care for the employee’s own healthy; qualifying issues that arise from a family member in the military on active duty. The only “eligible” employees are those who have worked for twelve months for the employer, those who work for an employer with more than fifty employees, and those who have worked at least 1,250 hours over the previous twelve months.
5. Due to eligibility restrictions, around 40 percent of U.S. workers are ineligible for the entitlements in the FMLA, only one-fourth of employers provide at least some period of fully paid “maternity related leave” and one-fifth provide no maternity related leave, paid or unpaid (Ray, Gornick, and Schmitt 2009).
6. This paper assumes that we all have certain positive rights to be treated with dignity and respect. It assumes that we all have certain positive duties to treat others with dignity and respect, regardless of their physical or mental condition.
7. This paper assumes that all individuals, regardless of their capabilities, are owed certain positive duties. The counterargument, that Ashley does not know what dignity is and does not understand what it means to be treated in a dignified or undignified manner, cannot be an argument against this paper’s assertions. This paper assumes we are all owed certain minimal positive rights, especially ones that will keep us alive.

WORKS CITED

Arno, P. S., C. Levine, and M. Memmott. 1999. “The Economic Value of Informal Caregiving.” *Health Affairs* 18, no. 2 (March): 182–88.

The Ashley Blog. 2010. Retrieved from <http://ashleytreatment.spaces.live.com>

“Burden.” n.d. In *Merriam-Webster Dictionary* online. Retrieved from <http://www.merriam-webster.com/dictionary/burden>.

- Campbell, T. 2010. "Ethics of Care." In *Ethics: A University Guide*, edited by R. H. Corrigan and M. E. Farrell, 79–107. Gloucester: Progressive Frontiers Press.
- Caplan, A. 2007. "Is "Peter Pan" Treatment a Moral Choice: Debate over Stunting a Disabled Child's Growth Pits Comfort against Ethics." MSNBC.com. Retrieved from <http://www.msnbc.msn.com/id/16472931>.
- Department of Health and Human Services Centers for Medicare & Medicaid Services. 2010. Invitation to apply for FY2011: Money follows the person rebalancing grant demonstration. Retrieved from https://www.cms.gov/CommunityServices/Downloads/MFP2011SolicitationOAGMFinal_July23.pdf.
- Diekema, D. S., and N. Fost. 2010. "Ashley Revisited: A Response to the Critics." *The American Journal of Bioethics* 10, no. 1: 30–44.
- "Dilemma." n.d. *Merriam-Webster Dictionary* online. Retrieved from <http://www.merriam-webster.com/dictionary/dilemma>.
- Disability Rights Education and Defense Fund. 2007. "Modify the System, not the Person." <http://www.dredf.org/news/ashley.shtml>.
- Dvorsky, G. 2006. "Helping Families Care for the Helpless. Institute for Ethics and Emerging Technologies." Retrieved from <http://ieet.org/index.php/IEET/more/809/>.
- Family Caregiver Alliance 2009. "Caregiving." Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2313.
- Ferleger, D., and P. A. Boyd 1979. "Anti-Institutionalization: The Promise of the Pennhurst Case." *Stanford Law Review* 31, no. 4: 717–52.
- Fineman, M. A. 2004. *The Autonomy Myth*. New York: The New Press.
- Frolik, L. A. 2008. *Residence Options for Older and Disabled Clients*. Chicago: ABA Publishing.
- Health Canada. 2010. Retrieved from <http://www.hc-sc.gc.ca/index-eng.php>.
- Kant, I. 2008. *On the Metaphysics of Morals and Ethics*. Radford, VA: Wilder Publications.
- Kaplan, D. 2003. "The Definition of Disability." Retrieved from <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>.
- Kittay, E. F. 1995. "Taking Dependency Seriously: The Family and Medical Leave Act Considered in Light of the Social Organization of Dependency Work and Gender Equality." *Hypatia* 10, no. 1: 8–29.

- . 1998. "Dependency, Equality, and Welfare." *Feminist Studies* 24, no. 1: 32–43.
- Liao, S. M., J. Savulescu, and M. Sheehan. 2007. "The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making." *Hastings Center Report* 37, no. 2: 16–20.
- Marcus, R. 1980. "Moral Dilemmas and Consistency." *The Journal of Philosophy* 77, no. 3): 121–36.
- Mason, H. E., ed. 1996. *Moral Dilemmas and Moral Theory*. New York: Oxford University Press.
- McConnell, T. 1996. "Moral Residue and Dilemmas." In *Moral Dilemmas and Moral Theory*, edited by H. E. Mason, 36–47. New York: Oxford University Press.
- Nagel, T. 1993. "Moral Luck." In *Moral Luck*, edited by D. Statman, 57–72. Albany: State University of New York Press.
- Nelkin, D. K. 2008. "Moral luck." *Stanford Encyclopedia of Philosophy*. Retrieved from <http://plato.stanford.edu/entries/moral-luck/#2>.
- Olmstead v. L.C. 527 U.S. 581 (1999).
- O'Shea, M. 2009. "Poverty, Development, and Mental Disability: A Need for Greater Attention at the International and Community Level." *TuftsScope: The Journal of Health, Ethics, and Policy* 9, no. 1: 22–23.
- Pavalko, E. K., and J. E. Artis. 1997. "Women's Caregiving and Paid Work: Causal Relationships in Late Midlife." *The Journals of Gerontology* 52B, no. 4: S170–S179.
- Ray, R., J. C. Gornick, and J. Schmitt. 2009. "Parental Leave Policies in 21 Countries: Assessing Generosity and Gender Equality." Center for Economic and Policy Research. Retrieved from http://www.cepr.net/documents/publications/parental_2008_09.pdf.
- Sander-Staudt, M. 2006. "The Unhappy Marriage of Care Ethics and Virtue Ethics." *Hypatia* 21, no. 4: 21–39.
- Shapiro, J. 2010, December 9. "A New Nursing Home Population: The Young." National Public Radio. Retrieved from <http://www.npr.org/2010/12/09/131912529/a-new-nursing-home-population-the-young>.
- Solinger, R. 2002. "Dependency and Choice: The Two Faces of Eve." In *The Subject of Care: Feminist Perspective on Dependency*, edited by E. Feder Kittay and E. K. Feder, 61–85. Lanham, MD: Rowman and Littlefield.
- Sobsey, D. 1994. *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* Baltimore: Paul H. Brookes.

- Spillers, R. L., B. S. David, D. K. Wellisch, Y. Kim, A. Matthews, and F. Baker. 2008. "Family Caregivers and Guilt in the Context of Cancer Care." *Psychosomatics* 49, no. 6: 511–19.
- Stadnyk, R. 2002. "The Status of Canadian Nursing Home Care: Universality, Accessibility, and Comprehensiveness." Atlanta Centre for Excellence for Women's Health. Retrieved from <http://www.acewh.dal.ca/eng/reports/The%20Status%20of%20Canadian%20Nursing%20Home%20Care.pdf>.
- Styron, W. 1979. *Sophie's Choice*. New York: Random House.
- Suthers, K. 2006. "Women Still Shouldering the Burden: Caregiving in the 21st Century." *Women's Health Activist Newsletter*, May/June 2006. National Women's Health Network. Retrieved from <http://nwhn.org/women-still-shouldering-burden-caregiving-21st-century>.
- United States Department of Health and Human Services. 2010. National Clearinghouse for Long-Term Care Information. http://www.longtermcare.gov/LTC/Main_Site/index.aspx.
- United States Department of Labor. 2010. *Wage and hour division: Family and Medical Leave Act*. Retrieved from <http://www.dol.gov/whd/fmla/index.htm>.
- Valenti-Hein, D., and L. Schwartz. 1995. *The Sexual Abuse Interview for Those with Developmental Disabilities*. Santa Barbara: James Stanfield Company.
- Vallentyne, P. 2002. "Brute Luck, Option Luck, and Equality of Initial Opportunities." *Ethics* 112, no. 3: 529–57.
- Williams, B. 1993. "Moral Luck." In *Moral Luck*, edited by D. Statman, 35–57. Albany: State University of New York Press.
- Williamson, G. M., K. Martin-Cook, M. F. Weiner, D. A. Svetlik, K. Saine, L. Hynan, and R. Schulz. 2005. "Caregiver Resentment: Explaining Why Care Recipients Exhibit Problem Behavior." *Rehabilitation Psychology* 50, no. 3: 215–23.