

Chapter 21

THE CONCEPT OF CARE ETHICS IN BIOMEDICINE

The Case of Disability

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My aim in this paper is to offer an oblique approach to the question of biomedicine and the limits of human existence by discussing the role of a care-based ethic in contemporary discussions of disability. Contemporary discussions of disability have resisted the notion that disability is essentially a matter of biology and medicine – that biomedicine has any exclusive right to define, or even to redress, the adverse living conditions that physiological impairments can impose on individuals. In this paper I endorse this critique, but at the same time want to urge caution in a concomitant rejection, which is also found in the disability literature, of the conception of care. Care addresses the limits and limitations of human existence, and disability is a condition in which humans at once encounter and challenge those limits. In this respect, disability shares with many issues of biomedicine questions of vulnerability and dependency. An ethics based on care offers distinct resources for discussions of biomedicine, but I will confine my remarks to exploring the importance of these for disability.

1. DISABILITY, INDEPENDENCE, DEPENDENCE, AND CARE

Care and disability are topics very close to me, both professionally and personally, as I have spent much of my philosophical career developing a care ethics and as I have been a caregiver for most of my adult years, a parent of a young woman with disabilities. Sesha is always part of my discussions on disability, both because it is through her that I have encountered questions surrounding disability, and so I feel it is important to

situate my own position in these discussions, and because as she is a member of a group of disabled persons who cannot speak for themselves, I feel compelled to speak on her behalf. I speak then – not for her, because that is first impossible and second presumptuous – but from the lessons I have learned through her and those who have helped me care for her. My daughter is a sparkling young woman, with a beautiful face and an even lovelier disposition. She is very significantly incapacitated, incapable of uttering speech, of reading or writing, of walking without assistance, or in fact doing anything for herself without assistance. She possesses a condition which is clumsily identified as mental retardation or developmental delay. I say clumsily because it is not clear that her problem is really the backwardness or slowness suggested by retardation or the delayed development that suggests that the development will come only a bit later. Although her cognitive functioning is limited, she loves music, water, good food, people, attention, love and life. (And so one might say that there is nothing amiss in her taste for the best life has to offer!) She is fully dependent and while, at the age of 34 she (like us all) is still capable of growth and development, it is quite certain that her total dependence will not alter much. She has lived at home with us till the age of 32, and now she has moved to a home with five other multiply and developmentally disabled young adults in a community in a rural setting. There is a way in which this move may be seen as isolating her, but in fact when we made the move, we discovered that she actually was more isolated while living at home with us “in the community.” But the care and level of activity she receives in her new home is exceptional, and I fear not the norm for such communities in the US and in most parts of the world. Many are, in fact, isolated in institutions in which they are supposed to receive care. My daughter’s disabilities always threaten to isolate her. And it is only with care, much of it and of the highest quality that she can be included, loved, and allowed to live a full and rich life. When I speak of disability, I think a great deal about the cognitive disability that marks her life and my concern is that persons who have these sorts of disabilities, as well as those who are involved in their care not be left out of not be left out of discussions of justice and moral personhood.

1.1 Dependence, Deviance, and Disability

Disability and care have a long and uncomfortable relation with one another. The same may be said for disability and dependence. While for some a physical dependence on caregivers enable them to carry on the activities of daily living, for many there is an economic dependence created by an inability to earn an adequate income given prejudice, discrimination

and lack of access to public spaces. There is also a dependence on social services, sometimes blamed as creating needs and thus sustaining the very dependence that these services were intended to relieve, a critique reminiscent of denunciations of welfare provisions more broadly conceived. When it is taken up by disability scholars and activists, the claim is that dependency is “created amongst disabled people, not because of the effects of the functional limitations on their capacities for self-care, but because their lives are shaped by a variety of economic, political and social forces which produces this dependency” (Oliver 1989: 17).

In a book entitled, *‘Cabbage Syndrome’: The Social Construction of Dependence*, the author writes:

The relationship between disability and deviance can be understood with reference to the freedom from social obligations and responsibility, explicit in the sick role model ... in the negative views of illness, disease and impairment that continue to hold sway throughout modern industrial capitalist societies. Because such societies are founded upon an ideology of personal responsibility, competition, and paid employment, any positive associations with sickness, such as the exemptions outlined above must be discouraged ... (Barnes 1990: 6)

As these two passages suggest, disability, particularly as it is cast as a “personal tragedy” is a concept that links dependency and deviance.

The default assumption is that a disabled person is a dependent person. Similarly, the disabled person is identified as deviant – deviant from a norm of typical species functioning (or form), which negatively effects self-sufficiency and social integration. The two presumptions come together, particularly within the Western industrialized nations, for the deviance that is perhaps especially salient is the deviation from one particular norm, that of independence, and hence is a deviance that renders one dependent. In a world in which independence is normative, the person with impairments comes to be isolated through a stigma which is linked to dependence and the need for care.

It is no accident then that the challenge disabled people in the US in the late 1960’s and early 1970’s mustered against their deviant status was entitled the Movement for Independent Living. This movement, created by people who were young, intellectually capable, white and largely male, did not interrogate the norm of independence, but affirmed it for a group that had previously been excluded. Their aims were inscribed in the important US antidiscrimination legislation, Americans with Disabilities Act (enacted in July 1990). That act states: “the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals” (ADA: (a), (8)). It is noteworthy that it goes on to say “the

continuing existence of unfair and unnecessary discrimination and prejudice ... costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity" (ADA: (a), (9)).

1.2 Care instrumentalized or repudiated

I do not think it is unfair to say that group of disabled individuals who so successfully lobbied for the ADA legislation viewed the provision of care in an essentially instrumental manner – much as most of us view our dependence on farmers. But the social dependence on farmers is taken by most to be relatively innocuous. In the case of care, the dependence has seemed for many with disabilities less benign. Provision that imposes itself on the individual and intrudes into his or her life may be identified with the oppressive forces that have the power to turn the disabled person into a suppliant.

Thus, it is not just the state and other institutions responsible for the lack of public access, the persistence of discrimination, the prevalence of need-based services, the labeling of persons as deviant and the exclusion of disabled people in decision-making that are excoriated for their part in the "creation of dependency." Professional providers of services and care-givers share the blame, as in the following passage from the British Council of Organisations of Disabled People: "... [T]he need to be 'looked after' may well adequately describe the way potentially physically disabled candidates for 'community care' are perceived by people who are not disabled ... which has led to large numbers of us becoming passive recipients of a wide range of professional and other interventions. But, however good passivity and the creation of dependency may be for the careers of service providers, it is bad news for disabled people and the public purse (BCODP 1987: 3.2, cited in Oliver 1989: 13).

Yet coming to the question of disability from the position (or "role") of a resolute carer of a disabled person, my daughter, I am invested in the idea that care is indispensable, and even central, to a good life for people with certain sorts of disabilities. (The claim is stated as it is to make it clear that I acknowledge that not all people with disabilities require care different – in manner or extent – from that of those not characterized as disabled and that due our human dependence, we each have required and are likely at some future time to require extensive care in order to survive and thrive. More of this in my concluding remarks.) Given that people with disabilities are attempting to cast off the perception of the disabled individual as hapless, in need of "looking after", and are working to retrieve independence in the face of practices and persons who reinforce and heighten the sense of

dependence, how is care to be regarded in the face of those limitations exacerbated by impairment.

2. BASIC CONCEPTS OF A CARE ETHIC

When I speak about an ethics of care I am speaking primarily of the conception of ethics that has been developed by feminists wanting to render visible and valuable activities that women have traditionally been charged with, namely the care and nurture of children, the ill, those with impairments who require assistance, and the frail elderly. A number of analytic philosophers who do not necessarily align themselves with feminist philosophy have also, of late, taken up work in an ethics of care. There has been a parallel development among some Continental philosophers, beginning with Emmanuel Levinas, who focus on care, although their work has been less influenced by feminist work. Most of my remarks will be limited to the feminist scholarship.

A care ethics as a feminist ethics challenges the univocity of male voices in ethical inquiry. The starting point for much feminist ethics of care, Carol Gilligan's empirically based claim that the abortion debate, structured as a conflict of rights – the rights of the fetus v. the rights of the women – fails to reflect decision-making of women who are faced with an unexpected pregnancy. Rather than ask if the fetus was a rights-bearing person, the women in Gilligan's study asked questions such as: Is it responsible to give birth at this time of my life? Am I prepared to take care of a child? How will giving birth to a baby now affect my relationship to my lover/my spouse/my parents/my children? How will my own vision of my possibilities be affected and can I be true to the person that others and I expect me to be? What harm will I do if I carry this pregnancy to conception, or if I abort this conception?

Rather than ask about rights, these women asked about responsibilities. Rather than frame the dilemma as a conflict between oneself and the unborn, they tended to think in terms of their relationships to a future child, current children, a spouse or lover, and other family. Rather than frame their concerns as matters of right, they were concerned about their ability to give care.

The term care can denote a labor, an attitude, or a virtue. As labor, it is the work of maintaining others and ourselves when we are in a condition of need. It is most noticed in its absence, most appreciated when it can be least reciprocated. As an attitude, caring denotes a positive, affective bond and investment in another's well-being. That labor can be done without the appropriate attitude. Yet without the attitude of care, the open

responsiveness to another that is so essential to understanding what another requires is not possible. That is, the labor unaccompanied by the attitude of care cannot be good care (see Kittay 1999).

Care, as a virtue, is a disposition manifested in caring behavior (the labor and attitude) in which “a shift takes place from the interest in our life situation to the situation of the other, the one in need of care” (Gastmans, Dierckx de Casterlé and Schotsmans 1998: 53). Relations of affection facilitate care, but the disposition can be directed at strangers as well as intimates.

2.1 A comparison of care- and justice-based ethics

The characteristics of care orientation to ethics are frequently expounded by offering a contrast to some more traditional justice-based approaches, especially Kantian-deontological and (to a lesser extent) utilitarian/consequentialist theories. (One might also wish to contrast a care ethics with a virtue-based ethics, although on some accounts, a care ethics is a variety of virtue ethics, see Slote 2001.)

Comparison of Care and Justice:

	<i>Justice</i>	<i>Care</i>
1. Moral Agent	Independent, autonomous self, equal or potentially so	Relational, dependent self, unequal in age, capacities, and/or powers
2. Moral Relations	Rights, relations of equality	Responsibilities, relations of trust
3. Deliberative Process	Principled, reason-based calculations, formal contexts	Contextual, narrative, emotion taken seriously
4. Scope of Decisions	Impartiality required, universal applicability	Partiality respected, applicability context-dependent
5. Moral Aim	Protect against conflict, adjudicate competing claims	Maintain connection, avoid violence
6. Moral Harm	Harm when clash between persons	Harm when connections are broken

It will be helpful to explore the contrast with reference to six questions to which a care-based and justice-based ethics offer different answers:

1. Who is the moral agent and what is the nature of moral agency?
2. What is the nature of moral relations?

3. What skills and processes are involved in moral deliberation and action?
4. What is the scope of moral decisions?
5. What are the aims of moral relations?
6. What constitutes moral harm?

Table 1 offers a rough summary of the responses. The following sections amplify these brief replies.

(1) The nature of the moral agency

Standard theories of justice begin with the autonomous individual moral agent who pursues his (sic!) desires and the fulfillment of needs in the context of a social situation in which there are other moral agents who do likewise. On a care ethics, each self is inextricably related to other selves. Their relationships play a constitutive role in the formation of their desires and in their identity (Tab. 1). Furthermore the self in theories of justice is a self-determining adult who is an independent agent. A care ethics does not presume that all agents in a situation demanding moral action are adults who are capable of self-determination and independence. Instead, the fact of our dependence on one another is seen as a part of our inevitable dependency and connectedness with one another. In my own elaboration of an ethic of care, I stress the nested dependencies in which we all find one another, as well as the interdependencies in which we all are engaged.

Tab. 1: Moral Agency

<i>Justice</i>	<i>Care</i>
Autonomous self	Self a self-in-relation (transparent self)
Self as bounded	Self as vulnerable
Independence, self determination valued	Dependence accepted as connection
Presumption of mature adult agents	Different ages capacities, abilities

(2) The nature of moral relations

Within traditional justice-based theories, moral relations are presumed to be among self-determining independent persons, equally situated and empowered, with whom they form associations that are voluntarily insofar as they are either chosen or affirmed. Moral interactions are bound by contractual, law-like sets of obligations or duties and a concomitant set of rights. We are bound to respect the rights of others as we expect others to

respect those we possess. The binding nature of these interactions is fixed in the form of a contract or understanding that I can only hope to have others respect my rights if I respect theirs in turn.

A care-based ethic does not presume that our ethical relations are self-chosen ones among equals, but maintains that we find ourselves in certain relationships to others, some of whom are better situated and have greater powers, others of which are with those who lack our capacities, who are not as well-situated as we are, and over whom we may have power. In engaging with others morally in situations of care, we need to assume a self that is transparent to the needs of another, rather than a self in which our actions are essentially self-directed as autonomy would generally require (See section 3 below). Moral relations are imbued with trust and trustworthiness, and willy nilly, we are beholden to the responsiveness and responsibility of those with greater power or capacity.

Tab. 2: Nature of Moral Relations

<i>Justice</i>	<i>Care</i>
Equality of relations	Inequality of relations
Between generalized others	Between concrete particular others
Emphasis on rights	Stress on responsibilities
Noninterference	Responsiveness
Bound by (voluntary) contractual relations	Bound by trust and dependence
Reciprocity	Asymmetrical giving and receiving

(3) Moral deliberation

How we do or should deliberate about the actions we take as moral agents is also quite different given the two ethical orientations. Within most theories of justice, deliberation is based on our ability to use an algorithm or procedure that will ensure a morally correct solution regardless of who deliberates and about whom one deliberates. These theories utilize a hierarchy of values defined by a set of principles. The categorical imperative and the attempt to maximize marginal utility are standard examples of such methods of moral deliberation. The idea is that given truthful and accurate inputs, a sound procedure carried out according to sound principles, we can

each reason so as to come up with *the correct* solution to a moral problem. We need only rely on our capacity to reason, and depending on the theory, a sense of duty, a sense of justice, or a prudential understanding of our own good. We are not called upon to be empathetic or sympathetic, to be kindly inclined, to have a significant range of emotional capacities, or even emotional responses to others within the moral sphere. These are either viewed as morally irrelevant or a hindrance to morally responsible judgement or action.

Coming to a moral decision or judgment within a care-based ethics is less guided by principle than on a justice based account, although principles can still play a role. Instead, a sensitivity to context, to the needs and capacities of those involved are often set within a narrative account that replaces or supplements context independent principles and hierarchical values. The requisite moral skills include a capacity to be responsive to need and an understanding of the specificity of the good for the affected persons. A recognition of the ways in which inequality of power or situation can turn from benevolence to abuse, and an ability to emotionally connect to another and their welfare are equally valued moral skills. Elsewhere I have spoken of the need of a carer to be transparent to the needs of the one in need of care. (Kittay 1999). By this I mean that one needs to be able to bracket one's own needs and wants and not to have these cloud one's perceptions of the needs of the one who is dependent on the carer. This transparency of self is a possibility of a self that views itself as relational.

Tab. 3: Deliberative Process

<i>Justice</i>	<i>Care</i>
Role of reason elevated	Value of emotion and shaped inclinations
Autonomous decision making	Transparent self-apparent heteronomy
Principles emphasized	Emphasis on contextual reasoning
Calculation of moral rights and wrong based on hierarchy of values	Narrative, specificity of context, culture, historical factors

(4) *What is the scope of morality?*

It is generally noted that justice-based theories tend to be applicable to settings governing relations between strangers, or acquaintances in non-intimate settings. Moral judgments, on this account, need to be universal in scope. Care is thought best reserved for private life and more intimate, less

rule-governed contexts. Within a justice tradition, proximity of those affected to the moral agent is irrelevant.

A care-based ethics remains sensitive to proximity, whether it be the relational proximity of family or friends or the geographical contiguity of neighbors and fellow citizens. What may be morally appropriate in dealing with strangers is not necessarily deemed morally appropriate in dealing with those close at hand, and what may be justifiable in the case of a neighbor may not be justifiable in the case of a child or parent. Valid moral decisions may well be partial, not impartial. It is deemed morally justifiable, and sometimes morally required to care more about those close at hand than those with whom we are more distant.

Tab. 4: Scope and focus of moral deliberations

<i>Justice</i>	<i>Care</i>
Formal contexts	Informal contexts
Public (in dispute)	Private (in dispute)
Universality	Context specific
Impartiality valued	Partiality accepted as deemed appropriate

(5) *What are the aims of moral relations?*

Perhaps the most radical and most relevant differences are directed to telos or point and purpose of moral relations. A justice-based ethics stresses the importance for people to be able to live their lives according to their own lights, free of unnecessary inference from others. Ethics is about the limits of that pursuit, insofar as others have the equal right to pursue their desires. The role of ethics is to avoid conflicts that arise from each self attempting to pursue their own desires.

These points are often encapsulated in the idea that the individual has certain claims upon others in the form of *rights*, rights which also protect one from the unwarranted interference of others. Each person is thought to have the full measure of rights that are compatible with others having the same full measure of rights. (That, at least, has been the aim of theories based on a *liberal* conception of justice.)

A care-based ethics stresses, first of all, the concern for the well-being of a person, and some, such as Stephen Darwall would add, the well-being of an individual *for their own sake*. That is, when we care for another we are

concerned with the well-being of that person as it serves that person's welfare for the purposes of that person's flourishing, not for the sake of the larger community or some abstract conception of goodness. It is this concern with the other's well-being for his own sake that places *responsibilities* on us for the other's care. The other's care is, however, not external to our own well-being for these affiliative relationships by which we care for another for their own sake are themselves constitutive of who we understand ourselves to be, for the self of a care-based ethic is a "self-in-relationship." (See also MacIntyre 1997; Gilligan 1982).

Tab. 5: Aim of Moral Relations

<i>Justice</i>	<i>Care</i>
Individuals live according to own lights, noninterference in rational life plans	Foster well-being (flourishing) of person for persons sake
Protect rights	Respond to need
Protect against and adjudicate conflict among persons	Foster, preserve connections, serve "progress of affiliative relationship" (Gilligan 1982: 170)

The aim of a care ethics becomes then the maintenance of relationship fostered through attention to and concern for the other's well-being. Self-sacrifice is often viewed as the ideal of a caring self, but as Gilligan importantly points out, when the self-sacrifice is complete, there is no self left and so there is no longer the possibility of relationship. The sacrifice of self may be spoken of as a "temptation of care" (as Sarah Ruddick 1989 puts it), rather than a virtue of care. This brings us at last to the final question.

(6) *What constitutes moral harm?*

Within a justice-based morality, moral harm is identified as the violation of rights or unwarranted intrusion in the form of paternalism, domination, or violence. It is to be treated unequally, discriminated against in employment, educational opportunities, political and social life, etc. for morally irrelevant reasons, and treated as an inferior with regard to the distribution of the benefits and burdens of social cooperation. Moral harm is seen as resulting from the clash of rights or interests among individuals.

In contrast, in a care-based ethic, moral harm results when important needs, especially of vulnerable persons are unmet, when our concerns elicit only indifference, when vulnerability arouses disdain and abuse rather than

care, and when human connections are broken through exploitation, domination, hurt, neglect, detachment or abandonment.

Tab. 6: Nature of Moral Harm

<i>Justice</i>	<i>Care</i>
When persons are interfered with unnecessarily, rights violated	When vulnerability and need are met with indifference, detachment, or abuse
Unequal treatment, discrimination	When persons are abandoned
When there is a clash of rights and interests among individuals	When connections between persons are broken

2.2 Temptations of virtues of care and virtues of justice

While one can argue that care and justice are both virtues that can serve as the basis of a moral theory, both can be seen as subject to certain temptations and limitations. Temptations are failures of a particular ethical stance, not merely the violation of that ethical ideal. A temptation of justice for example is a failure to be merciful. But to lack mercy is not yet to be unjust. It is to aim for justice but fall short in a manner characteristic of such an aim.

In the case of justice these temptations would also include being overly rule-bound, placing undue reliance on impersonal principles or institutions. An argument that justice fails us in an over-reliance on impersonal institutions is made by Alasdair MacIntyre, when he argues for the importance of the virtues with regard to a need for a standard of care. While legal enforcement of a standard of care is necessary, MacIntyre writes, “the networks of giving and receiving in which we participate can only be sustained by a shared recognition of each other’s needs and a shared allegiance to a standard of care ... [without which] laws will often be observed from fear of the consequences of doing otherwise, sometimes grudgingly and always in a way that has regard to the letter rather than to the spirit of the laws” (1997: 84–85). Interestingly, this suggests the need for the practice of care, even to enable the proper functioning of justice.

Temptations that undermine the practice of care include the sacrifice of self of which we spoke earlier. The contrary temptation, one that people with disabilities who need care are especially wary of, is the potential for the carer to lose sight of the separateness of the person for whom she cares. The danger is that she will impose her own conception of the good, or

alternatively an abstract notion of what is good for the other without sufficient attention to the subjectivity of the cared for. Here the separation of the self that justice-based ethics underscores is important to make caring work well.

2.3 Limitations of an ethic of care with special attention to disability

Having outlined features of an ethic of care, I want to redirect our attention to relevance of a care ethic for disability.

On the face of it, this ethic has a number of serious limitations for people with disabilities. First, as feminists have commented, if women doing the traditional work of caring do in fact exhibit an ethics based on care, should we not say that this is labor that women have been constrained to perform and so an ethics based on it is one borne of subjection. Is it not, as Nietzsche would have it, a “slave morality”? Is this the morality that is usefully adopted by a group of people who are struggling to emerge from a subordinate status?

Moreover, a care-based ethic, as we have seen, has been thought most suitable to informal and private domains. Applying it to the situation of disability would appear to favor the more individual, medical model of disability that is out of favor. Even if it is useful to people with disabilities in the informal, private contexts, why suppose that it can address the structural problems that a social model of disability highlights.

And finally, care, has been taken to be too closely tied to the very image of dependency that disabled people have in large measure tried to shed. Dependency implies power inequalities and a care-based ethics appears to embrace rather than challenge these inequalities.

3. WHAT A CARE-BASED ETHIC HAS TO OFFER DISABILITY THEORY: LIMITATIONS TURNED INTO ADVANTAGES

Although these limitations appear serious, I think they can be answered, and sometimes the limitations may be turned into advantages.

3.1 Slave morality?

To the charge that a care ethics is a “slave morality” we can reply that an ethic that springs out of practices arising from a subjugated position reveals that the subordinated do have a voice, and that it is one that needs to be

heard because it can inject new values into a society that does not treat some of its people well. To aspire to the values of an ethics as practiced by the dominant group may be to collude with the very values that subordinate some persons. For example, in talking about the idea of independence for physically disabled people who require aides to assist them with daily tasks, people with disabilities can inadvertently fall into morally questionable habits that mimic those of privileged groups who have taken for granted caring work, relegating it to unpaid or the worst paid labor.

Wanting to show how problematic the linkage of care, dependence and deviance is, Mike Oliver writes, "professionals tend to define independence in terms of self-care activities such as washing, dressing, toileting, cooking, and eating without assistance" (Oliver 1989: 14). Yet, he points out, "Disabled people, ... define independence differently, seeing it as the ability to be in control of and make decisions about one's life, rather than doing things alone or without help". I am suggesting that we still need to ask: "What about those who do the washing, dressing, toileting?"

Judy Heumann, one of the founders of the Independent Living Movement, wrote influentially: "To us, independence does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a normal body" (Heumann 1977).

This suggests that care, if it can be dissociated from the stigma of dependence, is not only compatible with independence of the sort that Heumann alludes to, but is in fact indispensable to it. But at the same time, we also need to consider that at least conceptually, if not strategically, destigmatizing dependency, or rendering it a value-neutral feature of the human situation and utilizing the resources of a care ethics will serve both the disability community and the larger community better than an emphasis on independence. For "independence" as the aim of a movement to include disabled people as full citizens of the human community, and with it the justice-based morality which here has been contrasted with a care-based one, only perpetuates the pernicious effects of the fiction that we can be independent. I suggest that the exploitative nature of care labor is likely to be exacerbated when viewed in the highly instrumental manner indicated by insisting that independence has to do with control and decision-making and nothing to do with needing assistance in carrying out daily tasks. (Also see my discussion of *Olmstead v. L. C. and E. W.* in Kittay 2000). The stress on independence makes it appear as if it would be preferable to have an aide replaced by a machine. Concomitantly, the person providing care comes to be seen as a pure instrument to the achievement of the independence of the disabled person. The fact that there is any relationship of dependency to another person appears as regrettable, insignificant, if inevitable fact. Annette Baier, addressing the absence of the concerns of domestics and care

workers within a theory focused on rights, speaks of these persons as “the moral proletariat” (Baier 1995: 55). Where is the independence and control of those who are mere instruments of another’s independence and control? What are we to presume of relationships between the person who gives care and the disabled person in need of that care? Elsewhere (Kittay 2001b) I argue, when caregivers are devalued, treated instrumentally, they in turn are more susceptible to devaluing those for whom they give care, particularly but not only, in the case of those with developmental and mental impairments. Is it not better to acknowledge one’s dependency on an other, and to examine ways in which there can be a mutually respectful relationship, based on a genuinely caring and respectful attitude. Is it not better to insure that relationships of dependency be replete with the requisite affective bonds, ones which can transform otherwise unpleasant intimate tasks into times of trust, and demonstrations of trustworthiness, gratifying and dignifying to both the caregiver and the recipient of care. Is it not preferable to understand relationships of care to be genuine relationships involving labor that is due just compensation and recognition. Here care and justice support rather than oppose one another.

Moreover, if by appealing to the nature of moral relationships envisioned within a care ethics we conceive of all persons as moving in and out of various relationships of dependence, through different life-stages and different conditions of health and functionings, the person with an impairment who requires the assistance of a caregiver is not the exception, the special case, but a person occupying what is surely a moment in each of our lives, and also a possibility that is inherent in being human, that is, the possibility of inevitable dependence. We see that we need to structure our societies so that such inevitable dependence is met with the care, resources and dignity required for a flourishing life. We again recognize that we need social arrangements enabling those who provide care to be similarly provided with the care, resources and dignity they require for their own flourishing and for the possibility of doing the work of caring well.

Finally, if we see ourselves as always selves-in-relation, we understand that our own sense of well-being is tied to the adequate care and well-being of another. Caregiving work is the realization of this conception of self, both when we give care generously and when we graciously receive the care we require.

3.2 Inequalities?

Critics of care ethics have often pointed out that the paradigm used has often been the mother and child relationship. Clearly this is not the sort of relationship that one wants to model adult relationships of disabled people

and care providers. We can at once grant this but insist that an ethics that acknowledges inequalities in situation and power are important if we are to avoid turning these inequalities into occasions for domination and abuse on the one hand, and paternalism on the other. Baier addressing the limitations of a rights approach to morality speaks of the sham in the “‘promotion’ of the weaker so that an appearance of virtual equality is achieved ... children are treated as adults-to-be, the ill and dying are treated as continuers of their earlier more potent selves ... ” She remarks, “This pretence of an equality that is in fact absent may often lead to a desirable protection of the weaker or more dependent. But it somewhat masks the question of what our moral relationships *are* to those who are our superiors or our inferiors in power” (1995: 55). She goes on to suggest that a morality that invokes this pretense of equality and independence, if not supplemented, may well “unfit people to be anything other than what its justifying theories suppose them to be, ones who have no interest in each others’ interests” (1995). That is, it may leave us without adequate moral resources to deal with genuine inequalities of power and situation that we face daily, and which not infrequently are conditions that certain impairments (apart from social arrangements) impose on us.

To deal with the inequalities that emerge out of the needs that are a consequence of certain impairments we require an ethic that can guide relationships between different sorts of care providers (family members, hands-on care assistants, medical personal) and people with different sort of care needs. The urgencies of need, whether they arise from medical emergencies, a breakdown in equipment needed for functioning, disabling conditions not addressable by accommodation, are ones that render disabled persons, (*and* not infrequently those who care for a disabled person whose welfare is part of the carer’s own sense of wellbeing) vulnerable. This is of course true of each of us, whether or not we are disabled. For instance, we generally come to medical professionals at a vulnerable moment. While paternalism is an inappropriate response on the part of professionals insofar as we may well be able to make or participate in important decisions about our lives, we are likely to require responsiveness to our need and to the particularity of our situation. It is precisely situations such as these that call for an ethic of care and responsibility (on the part of those with greater power and capacity toward those with less), rather than an ethic based on the reciprocity of rights of two equally empowered moral actors.

In raising the issue of vulnerability, it is worthwhile to point to a moral problem within the sphere of genetics and reproduction. We need to be aware of the vulnerability of prospective parents, as well as patients in the face of the presumed expertise of the physician operating in the arena of biomedicine. Issues such as genetic testing, selective abortion for disability,

surgical interventions of young children involve physicians, counselors, and bioethicists whose expertise render their relations to parents unequal at a time when parents are exceptionally vulnerable. We need to ask if a care-ethics, particularly its distinctive forms of ethical inquiry, for example the attentiveness to context and narrative (rather than hierarchical principles) can be helpful in providing better guidance – and better health care – for the disabled person and her family. I contend that the paradigm of justice-based ethics, the contractual model between equals is of less value in these situations.

A final point bears on distributive issues. In a model where equal parties participate in a fair system of social cooperation, the ruling conceptions are reciprocity, a level playing field, and fair equality of opportunity. On the assumption that all are equally situated and empowered, a conception of negative rights goes a long way to permit individuals to realize their own good. But differences in powers and situation require a more positive conception of rights and responsibilities toward those less well-situated or powered. Positive provisions are critical if people with disabilities are to be able to flourish – whether these are ramps, Braille in public areas or wheelchairs, help making one's home accessible, the service of home-care attendants, or a safe, enriching, stimulating environment in a protective setting. An ethic of care, if and to the extent that it can be made serviceable in the public domain becomes a stronger justification for positive rights insofar as care is seen as carrying out responsibilities we have for another's flourishing, not only the protection against undue interference or the mere assurance of equal opportunity. Ensuring equal opportunity to people is admirable when people are in a position to take advantage of the opportunities on offer, but many with significant disabilities are not in a position to take advantage of such opportunities even when accommodations are made. For persons with severe mental retardations, such as my daughter, Sesha, no accommodations can make her self-supporting regardless of antidiscrimination laws and every equal opportunity that may be legally available to her. Mental retardation poses a special challenge to the justice approaches that have predominated disability discourse. But even for those who are impaired in ways that are less disabling in our society, positive provision of attendants, equipment, appropriate housing and nonpublic sources of transportation require an attitude of care and concern that either is not well-captured in legal structures that enshrine principles of justice or must, as MacIntyre suggests, undergird formal systems in order for them to function properly.

3.3 Taking care ethics public

The above point concerning distributive justice should direct our attention to the claim that a care ethics is best suited for the private sphere of intimate relations and is not appropriate in the larger realm of public policy. This charge, if it is in fact a criticism, has been addressed by a number of authors. However, Joan Tronto (1989), for instance, argues that a care ethics, suitably developed, is the appropriate one to justify and guide welfare policy; Sarah Ruddick utilizes the ethical basis of “maternal thinking” to develop a peace politics (2001); Michael Slote (1987) defends the use of a care ethics to cover the ground usually reserved for justice, including ethical behaviour to those who are in different parts of the globe; and Virginia Held invites us to imagine what a society that governed social policy on a care paradigm might actually look like. These are only a few of the more prominent examples of efforts to show that an ethics of care need not be confined to intimate relationships. I have argued for a public ethic of care in which care and justice are both transformed in the accommodations a just society must make to be caring and caring relations must make to be just (Kittay 1999, 2001a, 2001b). Critical to my conception is the idea that we are all embedded in nested dependencies, and that a justly caring society must be one in which care of dependents is seen as central to the point and purpose of social organization. It is the obligation and responsibility of the larger society to enable and support relations of dependency work that takes place in the more intimate settings. (Gilligan 1987: 31) A society that makes adequate provisions for a flourishing life for people with disabilities will be one in which the fundamentals of a care ethic, such as our interrelationships and inextricable connectedness, our vulnerability and dependencies, our requirement of responsiveness to and responsibility for one another are recognized and valued along with our needs for respect and self-determination. These values will be reflected in public policies and in institutions, and there is nothing in these values and conceptions that inherently restrict them to the private sphere, even if that is where they are most apparent.

3.4 “The virtues of acknowledged dependence”

Rather than see the emphasis on dependence and connection as limitations, I have suggested that we see the emphasis of these in a care ethics as resources. Carol Gilligan talks about the ways in which a conception of relationship from a perspective of care and a perspective of justice may overshadow one another, citing two definitions of dependency offered by high-school girls she studied. One arises, “from the opposition

between dependence and independence, and the other from the opposition of dependence to isolation" (1987: 31–32). She develops the opposition: "As the word 'dependence' connotes the experience of relationship, this shift in the implied opposite of dependence indicates how the valence of relationship changes when connection with others is experienced as an impediment to autonomy or independence, and when it is experienced as a source of comfort and pleasure, and a protection against isolation" (1989: 14). We began the discussion with the question of the relation between care, dependence, and disability and in the definitions offered by these high school girls we see that where an ideology of independence is dominant, the positive experience of connectedness we can experience through dependence is eclipsed. To the extent that disability discourse aligns itself with that of independence, the understanding of dependence as a contrast to isolation is hard to fathom.

Acknowledging the inevitable dependency of certain forms of disability and setting them in the context of inevitable dependencies of all sorts, is another way to reintegrate disability into the species norm, for it is part of our species typicality to be vulnerable to disability, to have periods of dependency, and to be responsible to care for dependent individuals. We as a species are nearly unique in the extent to which we attend to the dependencies not only of our extended immaturity, but also of illness, impairment and frail old age. I propose highlighting the commonalities between different conditions of "inevitable dependencies", so that we can recognize that dependency is an aspect of what it is to be the sorts of beings we are. In this recognition, I hope we can begin, as a society, to end our fear and loathing of dependency.

4. CONCLUSION: REVISITING THE IDEAL OF INDEPENDENCE

When we see our dependency and our vulnerability to dependency as species' typical, we can recall that sense of dependence that is a respite from isolation. This is not an easy insight, but one articulated in a recent interview given by the comedian Richard Pryor (Gross 2000). The interviewer asked Pryor to speak about the Multiple Sclerosis that has incapacitated many of his bodily functions and will accelerate his death. Pryor said that as he lost old capacities, he had to learn new ones. Indeed, he maintained that the Multiple Sclerosis was "the best thing that had ever happened to me"; that his disease has been the occasion for the most important lessons he has had to learn about himself. He said that when, in order to walk from one end of a room to the other, a person *must* depend on another, he learns how to trust.

Learning to trust when he was vulnerable was the most valuable lesson he learned. This is a knowing that can alter us profoundly, especially when independence is touted as the hallmark of personhood.

As persons, in fact, spend a considerable portion of their lives either as dependents, caring for dependents or in relations where they have responsibility for dependents, the trust that Pryor had to learn when he became disabled – and the need for trustworthiness that warrants such trust – ought to be a feature of all our lives. The fiction of independence, and a fiction it is regardless of our abilities or disabilities, will not help us acquire the necessary moral skills – and may even as Baier suggested “unfit us” for the task.

Dependence may, in various ways be socially constructed, and unjust and oppressive institutions and practices create many sorts of dependence. But if dependency is constructed, independence is still more constructed. We cannot turn away from that fact and sufficiently rid ourselves of prejudices against disability, and certainly not for those whose disability cannot be disentangled from the need for care. We currently make resources needed by disabled people available on the supposition that such social “investments” will be cost effective, for these newly “independent” disabled will now be productive. Recall that the last finding that prefaces the ADA reads: “[T]he continuing existence of unfair and unnecessary discrimination and prejudice ... costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity” (*ADA*: (a), (9)). The commitment to the flourishing and maintenance of connection is absent in these provisions.

To mask inevitable dependency and valorize only a particular segment of human possibility strengthens the hand of those who refuse our collective responsibility to take care of one another and helps perpetuate the isolation of those with disabilities.

Among the many precious gifts I have received from my daughter Sesha has been to learn, as Alasdair MacIntyre puts it, “the virtues of acknowledged dependency” and the extraordinary possibilities inherent in relationships of care with one who reciprocates but not in the same coin, one who cannot be independent, but repays with her joy and her love.

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