

# The Ethics of Care, Dependence, and Disability\*

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*Abstract.* According to the most important theories of justice, personal dignity is closely related to independence, and the care that people with disabilities receive is seen as a way for them to achieve the greatest possible autonomy. However, human beings are naturally subject to periods of dependency, and people without disabilities are only “temporarily abled.” Instead of seeing assistance as a limitation, we consider it to be a resource at the basis of a vision of society that is able to account for inevitable dependency relationships between “unequals” ensuring a fulfilling life both for the carer and the cared for.\*\*

## 1. Preface

People with disabilities continue to suffer from discrimination in jobs, education, and housing, and are deprived of capabilities as basic as the freedom to move about. Even in aspects of life such as friendships, disabled people, especially if they are cognitively disabled, find themselves excluded (Reinders, 2008). Disability is in search of an ethics that will both articulate the harms faced by people with disabilities—discrimination that threatens dignity as well as well-being—and offer moral resources for redress.

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\*\* Abstract by Fabio Lelli.

In most dominant theories of justice, dignity is coupled with the capacity for autonomy. A person's well-being or welfare is usually a prerequisite to autonomy, but when individuals find themselves dependent on others (as many people with disabilities do) for self-care, economic security, and safety, the dignity which comes with autonomy appears threatened.<sup>1</sup> For this reason many people within the disability community share the views of Michael Oliver, who writes 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).

Instead people with disabilities have wanted to insist on their right to live independent lives and to be granted the same justice that is bestowed on people without disabilities, that is, the "temporarily abled." The need for care, or as many would rather say "assistance," is viewed not as a sign of dependence but as a sort of prosthesis that permits one to be independent. 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" (cited in Stoddard 1978, 2).

Much has been accomplished by the pioneering work of these disability advocates. In the United States it is most notably the *Americans with Disabilities Act* (ADA), 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]).

The ADA legislation views the provision of care as most of us view our dependence on farmers—instrumentally. For the most part, however, we do not encounter the farmers that feed us. We need only pay a middleman who pays the farmer for the goods. This yields an exchange between independent actors on par with other exchanges in the marketplace. Providers of care, in contrast, have to co-exist with the individuals they care for: They exert direct control over the minutiae of the life of their charge. The "middlemen" in the provision of care are the arbiters of whether and what kind of care is provided. The person in need of care is in their power with respect to intimate details of life, aspects of existence we often do not share except with those closest to us. This is an imposition and intrusion which can be oppressive and, when it turns the disabled person into a supplicant, is experienced as being at odds with dignity.

<sup>1</sup> Capability theory is in some measure exempt from this characterization as it offers a richer conception where dignity is tied to freedom of functioning or a set of capabilities that are taken to characterize a life of human dignity. These too presuppose a capacity to act on the freedoms or capabilities that are socially available. Some with disabilities, however, only come to possess these capabilities, or a subset of them, when they can depend on others for care.

The situation is worse still in a world where independence is the norm of human functioning. To the degree that the impairment requires a carer for the disabled person to live her life, care (and the carer) is stigmatized by dependency.

It is to this stigmatized dependency that the *British Council of Organizations of Disabled People* responds:

[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. (Cited in Oliver 1989, 13)<sup>2</sup>

Yet despite the achievement of the ADA itself and the opportunities it has opened, I believe there is much that is problematic in an approach that extols independence as the route to a dignified life and sees dependence as a denigration of the person. I worry that the emphasis on independence extols an idealization that is a mere fiction, not only for people with disability, but for all of us. The emphasis on choice leaves out many people with disabilities for whom making choices is problematic as their cognitive function may be seriously impaired. And the denigration of care and dependency tends toward an attitude that makes the work and value of the carers invisible, thus creating one oppression in the effort to alleviate another.

Instead I want to suggest that an ethics that puts the autonomous individual at the forefront, that eclipses the importance of our dependence on one another, and that makes reciprocal exchanges between equals, rather than the attention to other’s needs, the model of ethical interaction is not one to be preferred in the construction of an ethics of inclusion—at least not without the correction of an ethic of care. (Let me say parenthetically that a theory of justice based on capabilities avoids some of these difficulties but does not address dependency head-on and therefore I would argue still needs supplementation with an ethic of care.)

In casting doubt on some central tenets of disability theory, it is important to situate myself in this discussion. It is first as a parent that I have encountered the issue of disability. My daughter, a sparkling young woman, with a lovely disposition 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 has mild cerebral palsy, severe intellectual disability, and seizure disorders.

<sup>2</sup> Note a capability theory can only be baffled by such a view as the provision of such services seems to be exactly what would be called for by a capability theory.

Although her cognitive functioning appears limited, she loves music, bathing, good food, people, attention, and love. (Some of the finest things life has to offer.) She is fully dependent and while at the age of 40 she (like us all) is still capable of growth and development, it is quite certain that her total dependence will not alter much. I have been learning about disability from the perspective of one who is unable to speak for herself; and it is from her and her caregivers that I have come to have a profound appreciation of care as a practice and an ethic.

My daughter's disabilities always threaten her with a life of diminished dignity. It is only with care, and care of the highest quality, that she can be included, loved, and allowed to live a joyful and dignified 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 with such disabilities, as well as her caregivers, not be left out of considerations of justice and moral personhood.

## **2. Care Instrumentalized or Repudiated**

Coming to the question of disability from the position (or "role") of a resolute carer of a beloved disabled person, I am invested in the idea that care is an indispensable, and even a central good—one without which a life of dignity is impossible and which is itself an expression of a person's dignity. Elsewhere I argue that the ability of a being to give and receive care is a source of dignity for humans no less than the capacity for reason (Kittay 2005). 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, can care be recuperated as a valued and valuable concept? More specifically, can an ethic of care be relevant to the development of an ethic of inclusion that persons with disability may want to embrace?

The term "care" (in English) 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 requires skills on the part of the carer and uptake on the part of the cared for. 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. The 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 will not be good care (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 Casterle, and Schotsmans 1998, 53). Relations of affection facilitate care, but the disposition can be directed at strangers as well as intimates.

An ethic of care develops and refines the normative characteristics in the labor, the attitude, and the disposition. Most important for our purposes are the following ideas.

The *moral subject* is conceived as a relational self, one that is constituted in part by relationships important to a person's identity.

*Moral relations* occur not only between equals (who have voluntarily entered that relationship), but also among those not equally situated or empowered, individuals who find themselves in relationships that they themselves may not have chosen, as children find themselves in relation to parents they have not chosen.

*Moral deliberation* requires not reason alone, but also empathy, emotional responsiveness, and perceptual attentiveness. Although an ethic of care is often thought to be limited in its *moral scope*, confined to intimate settings, it can tread in areas usually occupied by justice as well, especially where practices of justice are inadequate to cover the contextual and narrative complexities of the situation.

Finally, *moral harm* is understood to be less a matter of the violation of rights, and more the consequence of failures in responsibility and responsiveness. Not the clash of interests, but the severing of valued connections is the harm an ethics of care attempts to avoid. As such, it aims at an ethics of inclusion, including all within a network of valued members.

### **3. Finding the Strengths in a Care Ethics in its Alleged Weaknesses**

Yet care-based ethics has been subject to criticisms that would render it unsuitable for an ethic of inclusion.

*First*, as feminists have commented, if the model of caring relations is work that women have traditionally been expected to do, work that has been part of their subjugation, then should we not say that an ethics based on caring labor is a "slave morality" as Nietzsche would have it? Can a group, such as disabled persons, struggling to emerge from a subordinate status, usefully adopt it?

*Second*, 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.

*Third*, a care-based ethic, it has been argued, really is only suited to the private domain. If this is right, then when applied to the situation of disability it would appear to favor the more individual, medical model of disability and cannot address the structural problems that a social model

of disability highlights. I want to argue that these very critiques in fact point to what is so valuable about an ethic of care for issues of disability.

### 3.1. *Care Ethics as a "Slave Morality"*

To the charge that a care ethics is a "slave morality" we can reply that an ethic that springs from the labor of subjugated persons reveals that the subordinated do have a voice. It needs to be heard because it can reveal value where none was previously acknowledged. It may prevent newly empowered people from colluding with the very values that previously were used in their own subjection.

For example, in extolling independence for physically disabled people, we can inadvertently fall into morally questionable habits that mimic those of privileged groups. When Heumann insists that independence is a "mind thing," not a "body thing," we still need to ask: What about those who do the body things, the washing, dressing, and toileting? Where is the independence and control of the persons providing care (the "moral proletariat" as Annette Baier (1995, 53) has called them) when they are mere instruments of another's independence and control (Kittay 2000)?

Is it not better to acknowledge our dependency as a feature of all human life, and to develop relationships that are genuinely caring and respectful? Is it not better for relationships of dependency to be replete with affective bonds that 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?

If we conceive of all persons as moving in and out of relationships of dependence through different life-stages and conditions of health and functionings, the fact that the disabled person requires the assistance of a caregiver is not the exception, the special case. The disabled person occupies what is surely a moment in each of our lives, a possibility that is inherent in being human. From this perspective, we reason that our societies should be structured to accommodate inevitable dependency within a dignified, flourishing life—both for the cared for, and for the carer. 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 receive it graciously.

### 3.2. *Relations of Care as Relations among Unequals*

Critics of care ethics have pointed out that the often used paradigm is the mother and child relation, which arguably is not a suitable model for

relationships between disabled adults and care providers. Yet we are not always equals even when adults—we are not equally situated or empowered when we are ill or incapacitated or faced with “experts” with greater knowledge and power. 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” (Baier 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” (ibid.). That is, it may leave us without adequate moral resources to deal with genuine inequalities of power and situation. 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* often carers whose own welfare is tied to that of the person for whom they care) vulnerable.

We need an ethic that can also help guide relationships between different sorts of care providers (family members, hands-on care assistants, medical personal) and people with different sorts of care needs. Paternalism is the only alternative to autonomy when autonomy is the norm of all human interaction. Cooperative, respectful, attentive relations are, I suggest, better alternatives than paternalistic responses toward those who depend on us in times of need.

A final point bears on issues of distributive justice. 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 empowered. Positive provisions are critical for people with disabilities to flourish, and an ethic of care provides a strong justification for such provisions as entitlements insofar as care requires carrying out responsibilities we have for another’s flourishing, whatever that may require. (Capability theory also serves here as a justification for positive rights.)

Ensuring equal opportunity to people is admirable when people are in a position to take advantage of the opportunities on offer, but some who

are disabled are not in this position. For persons with severe intellectual disabilities, such as my daughter Sesha, no accommodations, antidiscrimination laws, or guarantees of equal opportunity can make her self-supporting and independent. Even those less disabled require the positive provision of attendants, equipment, appropriate housing, specialized vans, and an attitude of care and concern in meeting whatever needs arise. An ethic of care requires that what is offered can be taken up by the person cared for. Unless the provisions are appropriate, they are not care.

### 3.3. *Taking Care Ethics Public*

That the distribution of public resources can be a matter of care counters the notion that a care ethics is suited only for the private sphere of intimate relations and not for public policy. Many have already addressed the different ways the scope of care extends beyond intimate relations. Joan Tronto (1993), Sarah Ruddick (1989), Michael Slote (2001), Virginia Held (2006), and Nel Noddings (2002), among others, invite us to imagine what a society that governed social policy on a care paradigm might actually look like. The virtues that guide care in intimate spheres can introduce new values into the public domain. I have argued for a public ethic of care based on the idea that we are all embedded in nested dependencies. 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, for that is the point and purpose of social organization—or at least a major one.

## 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 cites 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” (Gilligan 1987, 31–2). By placing these two contrasting definitions of dependence side by side, we see that the dominance of an ideology of independence will eclipse the positive experience of connectedness we can experience through dependence.

Acknowledging the inevitable dependency of certain forms of disability, setting them in the context of inevitable dependencies of all sorts, is another way to reintegrate disability into the species norm. 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 unique (or nearly so) in the extent to which we attend to

dependency, most likely because we experience the long dependency of youth. When we recognize that dependency is an aspect of what it is to be the sorts of beings we are, we, as a society, can begin to confront our fear and loathing of dependency and with it, of disability. When we acknowledge how dependence on another saves us from isolation and provides the connections to another that makes life worthwhile, we can start the process of embracing needed dependencies.

In a recent interview, the American comedian Richard Pryor who now has Multiple Sclerosis, said that as he lost old capacities, he had to learn new ones; that the Multiple Sclerosis was in fact “the best thing that had ever happened to me.”<sup>3</sup> The incredulity of the interviewer was palpable. Then Pryor explained that he had lived a life in which he had felt he could never trust anyone. Because, in order to walk from one end of a room to the other, a person *must* depend on another, he learned how to trust for the first time in his life: This, he replied, was the best thing that ever happened to him.

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. Dependence may in various ways be socially constructed, and unjust and oppressive institutions and practices create many sorts of dependence that are unnecessary and stultifying. 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. 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 independence touted is advanced as a cost-saving, not as a commitment to the flourishing of each disabled person.

I have received from my daughter Sesha a knowledge of, as Alasdair MacIntyre puts it, “the virtues of acknowledged dependency” (MacIntyre 1999) and of the extraordinary possibilities inherent in relationships of care toward one who reciprocates, but not in the same coin; one who cannot be independent, but makes a gift of her joy and her love.

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<sup>3</sup> T. Gross, Interview with Richard Pryor, *Fresh Air*, 27 October 2000 (radiophonic interview).

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