

# THE DISABILITY CRITIQUE OF CARE

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## I INTRODUCTION

Ethics of care is now recognised as providing a significant contribution to philosophical and ethical analysis. The literature on it is voluminous.<sup>1</sup> However, there have been few attempts to criticise it. That may well be because the theory is so wonderful no one could disagree with it! More seriously, this may be that, rather than criticise it, many mainstream ethicists have side-lined ethics of care to being ‘just’ about interpersonal relationships of a certain kind and so not of broader significance. Such views may indicate a lack of understanding of what is claimed by care ethicists or a failure to appreciate the richness of the literature.

In this article, I want to address one body of writing that has taken ethics of care seriously and has produced some genuinely powerful and constructive criticism: writing from disability studies. This article will start by outlining very briefly the major aspects of ethics of care. It will then explore why the theory has received criticism from some disability study writers, before considering how ethics of care might take account of the important issues raised by the critique. This critique is of interest to elder law scholars because some older people are disabled and/or in caring relationships with disabled people.

### *A The Ethic of Care*

Joan Tronto explains that ethics of care is:

...a set of moral sensibilities, issues and practices that arise from taking seriously the fact that care is a central aspect of human existence...a species activity that includes everything that we do to maintain, continue and repair our ‘world’ so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web.<sup>2</sup>

Under ethics of care, the practice of caring would be highly valued within society. A central role for society is to meet the essential needs of citizens. In many cases this must be by care. Far from being hidden, caregivers would come to represent a norm, fulfilling an essential societal obligation. Social structures and attitudes would need to be set up to encourage and

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<sup>1</sup> Leading works on ethic of care include: Carol Gilligan, ‘Moral Orientation and Moral Development’ in Eva Feder Kittay and Diane Meyers (eds), *Women and Moral Theory* (Rowman and Littlefield, 1987); Joan Tronto, *Moral Boundaries* (Routledge, 1993); Selma Sevenhuijsen, *Citizenship and the Ethics of Care* (Routledge, 1998); Ruth Groenhout, *Connected Lives: Human Nature and an Ethics of Care* (Rowman and Littlefield, 2004); Virginia Held, *The Ethics of Care* (Oxford University Press, 2006); Daniel Engster, *The Heart of Justice. Care Ethics and Political Theory* (Oxford University Press, 2007); Jo Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (Cambridge University Press, 2009); Jonathan Herring, *Caring and the Law* (Hart, 2013).

<sup>2</sup> Tronto, above n 1, 12.

enable caring relationships. A broad range of social policies promoting care would be required.<sup>3</sup>

Ethics of care would challenge the way legal rights and responsibilities are commonly understood. Much of the law is based on the assumption that we are competent, detached, independent people who are entitled to have our rights of self-determination and autonomy fiercely protected. Legal rights and rules operate to draw boundaries around ourselves and protect us from interference from others. However, the reality is that we are ignorant, vulnerable, interdependent individuals, whose strength and reality is not in our autonomy, but our relationships with others.<sup>4</sup> The law should start with a norm of interlocking mutually dependent relationships, rather than an individualised vision of rights.<sup>5</sup>

The central themes of ethics of care are as follows:<sup>6</sup>

### *1 Care is Part of Being Human*

We all have needs and caring for others in meeting these needs and having our needs met by the care of others is a universal experience. Wendy Holloway argues that ‘care is the psychological equivalent to our need to breathe unpolluted air’.<sup>7</sup> In a person’s lifespan, the extent of caring may vary during different ages. At every point in our lives we are either being cared by or caring for another – often both at the same time. In failing to acknowledge care work properly, the law is missing a critical aspect of life.

### *2 Care is a Good Part of Life*

Not only is care an inevitable part of life; it is a good part of life. Care should be treasured and valued. As Robin West puts it:

Caregiving labour (and its fruits) is the central adventure of a lifetime; it is what gives life its point, provides it with meaning, and returns to those who give it some measure of security and emotional sustenance. For even more of us, whether or not we like it and regardless of how we regard it, caregiving labour, for children and the aged, is the work we will do that creates the relationships, families, and communities within which our lives are made pleasurable and connected to something larger than ourselves.<sup>8</sup>

Care is the manifestation of that most basic moral value: love. It involves meeting the needs of others, which is a primary good.

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<sup>3</sup> The payment of carers has been said to carry dangers of causing the ‘marketisation of intimacy and the commodification of care’: Clare Ungerson, ‘Cash for Care’ in Madonna Harrington Meyer (ed), *Care Work: Gender Class and the Welfare State* (Routledge, 2000) 69.

<sup>4</sup> Christopher Meyer, ‘Cruel Choices: Autonomy and Critical Care Decision-Making’ (2004) 18 *Bioethics* 104.

<sup>5</sup> Robin West, *Caring for Justice* (New York University Press, 1997) 356.

<sup>6</sup> For a more detailed analysis of these points see Herring, above n 1, chs 2 and 3.

<sup>7</sup> Wendy Holloway, ‘Introducing the Capacity to Care’ in Wendy Holloway (ed), *The Capacity to Care: Gender and Ethical Subjectivity* (Routledge, 2006).

<sup>8</sup> Robin West, ‘The Right to Care’ in Eva Feder Kittay and Ellen Feder (eds), *The Subject of Care: Feminist Perspectives on Dependency* (Rowman & Littlefield, 2002) 89.

### 3 Emotions are Ethically Significant

Emotions are an important source of moral insight for care ethicists because emotions are central to good care. Trust, sympathy, empathy and sensitivity are requisites of high quality care. If the response to a dilemma undermines these emotions it will undermine the care. However, the law tends to be suspicious of emotion. Much of the law emphasises the importance of rationality and intellect and downplays the importance of emotion. The concepts of mental capacity, informed consent, and compliance with standards expected by a responsible body of opinion, all privilege in legal discourse logical thought and sound judgement. These are important concepts, but they can overlook the importance of emotion. The love which goes on caring and being cared for, and the grief, disappointment, frustration, anger and despair, which are all part of life, find no place.<sup>9</sup> Too much emotion can lead one to being found to lack capacity and one's views discounted.<sup>10</sup> Ethics of care seeks to acknowledge the role that both emotion and rationality play in relationships.<sup>11</sup>

### 4 Intermingled Interests

Ethics of care is based on the belief that people are relational. People understand themselves in terms of their relationships. They do not seek to promote only their own interests, not because they are 'selfless', but because their interests are tied up with the interests of others. They cannot seek to promote their own interests with no attention paid to others. If good things happen to those they are in a positive relationship with then that is good for them. And the same is true for bad things.

An ethic of care, therefore, takes a particular view of the nature of the self, one that is constructed through and finds its meanings in relation to others.<sup>12</sup> Supporters of ethics of care do not need to entirely reject the notion of an individual self, but simply recognise that its identity and nature can only be appreciated through relation to others.<sup>13</sup> In relationships of caring and dependency, interests become intermingled.<sup>14</sup> We do not break down into 'me' and 'you'.

### 5 The Importance of Responsibilities

Ethics of care emphasise the importance of responsibilities within caring relationships. While not necessarily opposed to the idea of legal rights, they are wary of their dominance in the legal discourse, and the danger that rights are used in an individualistic way. Supporters of ethics of care argue that rather than the primary focus of the legal or ethical enquiry being whether 'is my right to do X?', the question should be 'what is my proper obligation within the context of this relationship?'<sup>15</sup> Rather than the law promoting people's freedom from

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<sup>9</sup> Occasionally it peeps through (see the refusal of the medical team who had done so much work to care for the patient in *Re B (Adult: Refusal of Medical Treatment)* [2002] All ER 449 that they felt unable to switch off her life support machine as the Court ultimately ordered).

<sup>10</sup> See, eg, *Re MB* [1997] EWCA civ 1361.

<sup>11</sup> Simon Blackburn, *Ruling Passions* (Clarendon Press, 1998).

<sup>12</sup> Susan Sherwin, 'A Relational Approach to Autonomy in Health Care' in Susan Sherwin (ed), *The Politics of Women's Health* (Temple University Press, 1998) 19.

<sup>13</sup> Jocelyn Downie and Jennifer Llewellyn, *Being Relational* (UBC Press, 2011).

<sup>14</sup> Tom Shakespeare, *Help* (Venture, 2000).

<sup>15</sup> Held, above n 1, 15.

responsibility, the focus should be on how the law can enable people to fulfil their responsibilities. Rights primarily exist to enable people to carry out their responsibilities.<sup>16</sup>

Care ethics take a very different approach to our understanding of how responsibilities arise. The classic liberal perspective is that one is 'born free' and that any responsibilities one takes must be in some sense voluntarily assumed. However, for an ethic of care approach, with its starting point being that people are relational, then the supposition is that there will be responsibilities for others. We are born into relationships which carry responsibilities with them. So the response to a person in need is not an assessment of the extent you might owe them an obligation to assist, but rather an assessment of how one can meet that need, given other caring responsibilities.<sup>17</sup>

### *6 The Importance of Non-Abstraction*

One of the key aspects of care ethics is the rejection of abstract moral rules. Instead we should start with the context and concrete reality of the particular situations and the individuals and their relationships and characteristics. What might work for one group of people in one situation, will not work in another. Hence it is that those taking an ethics of care approach will often say in the face of an ethical dilemma, "well it all depends on the circumstances of the case". That is because it does. This is, in part, a corollary of the nature of care. Care seeks out the needs of the particular individual in their particular context. What meets one particular individual's needs is inevitably personalised and not susceptible to generalised rules. Similarly, the extent to which a person may be expected to provide care involves an assessment of their particular circumstances.

## II THE DISABILITY CRITIQUE

A strong attack on the notion of ethics of care has come from some writing from a disability perspective.<sup>18</sup> Before explaining the nature of that challenge, it is important to understand the background, which is the debate over the nature of disability.

### *A The Nature of Disability*

As is well-known, there has been considerable debate over whether disability should be seen on an individual or social model. For the individual model the problem with disability lies within the individual. The cause of any problems flowing from disability is the limited functional or psychological loss the individual is thought to suffer from. The appropriate response to disability is to eliminate disability, by curing it or (more controversially) preventing disabled people being born the first place. If this is not possible we should attempt to mitigate the disadvantages flowing from disability.<sup>19</sup>

The social model, by contrast, sees the problems flowing from disability being society's failure to provide the necessary services to ensure no difficulties flow from the difference in function or psychology. This model argues that society chooses to provide accommodations for some limitations people face (be it shops, transport, sewerage, etc), but not for others. We

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<sup>16</sup> Fiona Williams, 'The Presence of Feminism in the Future of Welfare' (2002) 31 *Economy and Society* 502.

<sup>17</sup> Selma Sevenhuisen, 'Caring in the Third Way: The Relation between Obligation, Responsibility and Care in *Third Way Discourse*' (2000) 20 *Critical Social Policy* 5.

<sup>18</sup> For an excellent discussion see Tom Shakespeare, *Disability Rights and Wrongs* (Routledge, 2006).

<sup>19</sup> Janet Radcliffe Richards, 'How Not to End Disability' (2002) 39 *San Diego Law Review* 693, 695.

all have a range of limitations and society is willing to meet some, but not all, of them. Those limitations which society does not meet are labelled as disability. The defining characteristic of a disability on this model is not located within the individual, but rather the lack of provision within society. The 1976 Union of Physically Impaired Against Segregation (UPIAS), adopting the social model, defined disability in the following way:

Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability,' of people with such impairment. Thus, we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.<sup>20</sup>

This debate between the social and individual models of disability is complex and has become intense. This article is not the place to explore all the issues properly. We are now in a position to understand the criticisms of an ethic of care launched by those writing from a disabilities' study perspective.

### *B Care and the Social Model of Disability*

Care, it is said by many care ethicists, is a good thing because it meets the needs of others. Put that way it is easy to see how it plays into the individualised model of care. This way of understanding care may be said to reinforce the individualised model of disability because it locates the 'problem' in the body of the disabled person, which is met by the care. In particular it assumes a norm for bodies, and disabled bodies are those departing from this norm, and so requiring care which can bring them back to the norm.

One particular way that care ethics is in danger of doing this is by emphasising the burdens of care. A common tactic (understandably) of organisations promoting the interests of carers is to emphasise the burdens and disadvantages that carers suffer because of their work.<sup>21</sup> This impliedly paints the disabled person as the cause of disadvantage. Unintentionally it can imply that disability is 'a problem', which carers pay the cost of solving.

### *C Care and Power*

Ethics of care assumes that care is good and something to be prioritised. This overlooks the 'dark side of care'.<sup>22</sup> In particular it ignores the paternalistic edge that can accompany care.<sup>23</sup> As one disabled person wrote:

We are who we are as people with impairments, and might actually feel comfortable with our lives if it wasn't for all those interfering busybodies who

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<sup>20</sup> Union of Physically Impaired Against Segregation, *Fundamental Principles of Disability* (UPIAS, 1975).

<sup>21</sup> Carers UK, *Campaigning for a Better Care Bill* (Carers UK, 2013).

<sup>22</sup> Michael Fine, *A Caring Society?* (Palgrave, 2007) 4.

<sup>23</sup> Shakespeare, *Help*, above n 14.

feel that it is their responsibility to feel sorry for us, or to find cures for us, or to manage our lives for us, or to harry us in order to make us something we are not, i.e. 'normal'.<sup>24</sup>

To similar effect Richard Woods contends:

Disabled people have never demanded or asked for care! We have sought independent living, which means being able to achieve maximum independence and control over our own lives. The concept of care seems to many disabled people a tool through which others are able to dominate and manage our lives.<sup>25</sup>

What is captured in these quotations, but often lost in the ethics of care literature, is the way that caring for another can amount to an exercise of power. Caring can involve the carer in identifying the need and determining how best to meet it. Zygmunt Bauman warns that 'the impulse to care for the other, when taken to its extreme, leads to the annihilation of the autonomy of the other, to domination and oppression'.<sup>26</sup> Julia Twigg's recent research on older people's experiences of being bathed highlights this quite clearly:

One person, strong and able, stands above and over another who is frail and physically vulnerable, forced to rely on their strength and goodwill. Being naked in the face of someone who is not, contains a powerful dynamic of domination and vulnerability, and it is often used in situations of interrogation and torture as a means of subjugating the individual.<sup>27</sup>

Disabled people are already marginalised by society can be further disempowered by the nature of care. At its worst care can objectify the disabled person. This, it should be emphasised is often the result of 'carers' trying to be kind.<sup>28</sup> Christine Kelly writes:

In the context of disability, care is haunted by the spectres of institutionalization, medicalization and paternalistic charities which, in varying degrees past and present, systematically marginalize people with disabilities... In the name of 'caring for' individuals or society at large, disabled people have been subjected to multiple forms of oppression, including forced sterilization, painful and ineffective physical 'therapies', physical and emotional abuse, and of course, institutionalization.<sup>29</sup>

Bernhard Weicht<sup>30</sup> has identified these issues as arising particularly in the discourses on care of older people. He argues that the writing can construct the carer as young, active and

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<sup>24</sup> Colin, quoted in Sally French and John Swain, 'Whose Tragedy? Towards a Personal Non-Tragedy View of Disability' in John Swain, Sally French, Colin Barnes and Carol Thomas (eds) *Disabling Barriers – Enabling Environments* (Sage, 2004) 54.

<sup>25</sup> Quoted in Shakespeare, *Help*, above n 14, 63.

<sup>26</sup> Zygmunt Bauman, *Postmodern Ethics* (Blackwell, 1993) 11.

<sup>27</sup> Julia Twigg, 'Carework as a Form of Bodywork' (2000) 20 *Ageing and Society* 389.

<sup>28</sup> Anita Silvers, 'Reconciling Equality to Difference: Caring (f)or Justice for People with Disabilities' (1995) 10 *Hypatia* 30, 33-4.

<sup>29</sup> Christine Kelly, 'Making "Care" Accessible: Personal Assistance for Disabled People and the Politics of Language' (2011) 31 *Critical Social Policy* 562, 565.

<sup>30</sup> Bernhard Weicht, 'Embracing Dependency: Rethinking (In)Dependence in the Discourse of Care' (2010) 58 *Sociological Review* 205.

independent, while the older person receiving care is passive and dependent. He notes how the older person is often used as the epitome of the body needing care in public presentations of care. Further, he highlights that fear of becoming 'a burden' and needing care has become a major fear for older people, or at least is presented as something they should be concerned about.

#### *D From Care to Assistance*

Many writing from a disability study perspective have argued that we need to shift away from the notion of care, and towards attendant services. For example, the Centre for Independent Living in Toronto posits a clear definition of attendant services:

Attendant Services are physical assistance with routine activities of daily living as directed by the consumer. The consumer is responsible for the decisions and training involved in his/her own assistance.

Attendant services include: bathing and washing, transferring, toileting, dressing, skin care, essential communications, meal preparation.

Attendant services do NOT include: professional services such as nursing care, physiotherapy, occupational therapy, respite care, physician services, 'care' or taking responsibility for the person with a disability.<sup>31</sup>

The aim of this shift is to increase the independence of the disabled person.<sup>32</sup> They want to control and utilise help to achieve independence, not be the passive recipients of care. Care, it is argued, should be a tool that the disabled person uses to achieve independence.<sup>33</sup> The focus should be on empowerment, control and choice for those with disabilities, even if self-sufficiency is not possible. The terms 'helper' or 'personal assistant' (rather than carer) are preferred in an attempt to remove any implication that the person needing care is suffering a particular misfortune that needs attention, or that the person is passive in the enterprise.<sup>34</sup> The helper is assisting the disabled person to achieve what they wish for.

### III RESPONSES OF CARE ETHICS

Some writers in the light of these points have identified a tension between feminist ethics of care writers and disability activists. Clare Beckett puts it:

To the disabled people's movement, care is a necessity on the road to equal rights and citizenship. To women, care relationships are premised in capitalist economic and family relationships and can be both oppressive, and, conversely, sources of personal identity claims.<sup>35</sup>

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<sup>31</sup> Centre for Independent Living in Toronto (2010), cited in Christine Kelly, 'Re/Moving Care from the Ontario Direct Funding Program: Altering Conversations among Disability and Feminist Scholars' (2013) *Social Politics* forthcoming.

<sup>32</sup> Nick Watson et al, '(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model' (2010) 38 *Sociology* 221.

<sup>33</sup> Jenny Morris, 'Impairment and Disability: Constructing an Ethics of Care that Promotes Human Rights' (2001) 16 *Hypatia* 1.

<sup>34</sup> Kelly, above n 29, 562.

<sup>35</sup> Clare Beckett, 'Women, Disability, Care: Good Neighbours or Uneasy Bedfellows?' (2007) 27 *Critical Social Policy* 360, 360.

A slightly different tension is between the image of care as a worthy value to be elevated and care as the paternalistic exercise of power.

The writing from disability studies is a powerful critique of care. It must be a cause of some embarrassment that much of the writing on care ethics has had little discussion of those receiving care. Much is written in the care literature on the social isolation of carers; the personal and economic disadvantage of carers; and the lack of recognition that carers are given in society. This is all welcome and important, but in making such points those 'receiving' the care and the disadvantages they face have also been ignored. Further, there is the possibility that the abuse of care gets overlooked in the care literature.

That said, some of the critique overlooks the nuances within the literature. Joan Tronto, for example, has been clear that a central part of care is responsiveness: consideration of the position of others as they see it and responding in the way they want it.<sup>36</sup> Several writers have emphasised how an ethic of care requires an awareness of, and response to, the abuse that can arise within caring relationships.<sup>37</sup>

I do not think that these criticisms require an abandonment of ethic of care by any means, and to some extent they may be a criticism of how care is presented in the political campaigns rather than the academic writing on the issue. Clare Beckett correctly identifies the key issue: 'to what extent are disempowering factors and inequality inherent in conceptualizing care?'<sup>38</sup> I think they are not, but that requires more work in understanding the definition of what ethics of care is seeking to promote.

#### *A Caring Relationships Not Carers*

I think it is true that many writers on care have presented the issue from the carer's perspective, such as the calls for 'carers' rights'. Care has been presented as a uni-directional activity. Attempts to define care, the central aspect of an ethic of care, have tended to reinforce the notion that we are looking at an activity which one person does to another. It is for this reason that in my book on caring I argued that rather promoting 'care' we should promote 'caring relationships'. My hope was that in using this terminology the contributions of both parties would be recognised.

The traditional division between the carer and person receiving care fails to capture the dynamic in caring relationships. It tends to emphasise the vulnerability of some, rather than recognising the vulnerability of all. It paints the 'cared for' as passive. By talking of caring relationships, we can recognise that we are all givers and receivers of care. Such relationships will change over time so that pigeonholing the parties into categories of carer and care receiver become artificial. It also helps to reinforce the fact that we are all in a network of caring relationships, sometimes playing a different role in each. As Clare Beckett puts it: 'to be caring or cared for are not positions, attributes or roles that are necessarily oppositional or dualistic in practice, but are part of the weave of any social relationship'.<sup>39</sup>

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<sup>36</sup> Tronto, above n 1, ch 1.

<sup>37</sup> Herring, above n 1, ch 7.

<sup>38</sup> Beckett, above n 35, 360.

<sup>39</sup> Ibid 362.

Janet Fink argues that the failure to include evidence of the lives of disabled people has had several effects:

First, it has perpetuated the continuing tendency of discourses of care to constitute disabled people as an inevitable burden on their families, thereby setting up a dichotomy between ‘normal’ families and families with disabled members. This suggests that one set of relationships is benign and ‘the other is problematic and pathological’. Second, it has elided the ways in which care relationships can be understood as being built around elements of reciprocity and interdependence, failing, thereby, to acknowledge that in some places and at some times, we have all experienced giving and receiving care.<sup>40</sup>

These are good points, but I would argue that the promotion of a caring relationship is preferable to talk of a disabled person having a personal assistant, as many writing from a disability studies perspective have argued for four reasons.

First, the dialogue of employing people to direct personal assistance is only plausible for some people with disability, perhaps the most articulate and vocal. For the profoundly disabled and those with intellectual challenges the responsibility of directing their care may be an impossibility or a burden. The model of directive assistance only works for some disabled people.

Second, the language faces the many of the same problems as the carer/cared for dialogue does in reinforcing the separation rather than the combination. As argued earlier (and will be returned to shortly), identities become merged in caring relationships. Care is a two-way process. Restricting people into an employer/employee model will be artificial in many cases.

Third, it probably does not reflect the emotion aspect of care. The notion of assistance being used as a tool to independence does not capture the nature of what is going on. Imagine, for example, that there were mechanical or robotic devices available that could perform tasks that might otherwise be done by other humans. Apparently a human-washing machine, known as an ‘assisted-care bath’ has been created. Let us assume for a moment that a robot could be devised to carry out certain tasks, it is not clear that the level of care understood in the round would improve. The lack of social interaction and connectedness would be lost.<sup>41</sup>

Finally, the language of personal assistance will do nothing to improve the conditions of those providing care. Diemut Bubeck writes:

A carer can easily feel exhausted by the seemingly or often actually never-ending demands of others and by the fact that her efforts are directed towards looking after others’ well-being. Worse than this, she may even feel used by those she cares for, like cheap labour or even like a servant or slave, neither of whose lives are their own. She may feel this way because, in fact, she does not have a life of her own, because her life is filled with caring for others. She may feel completely out of control and powerless because as a carer she is at the constant beck and call of others. These feelings may be seen to be linked to the fact that, as a carer, a person will be extremely vulnerable to others’ demands

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<sup>40</sup> Janet Fink, *Care Personal Lives and Social Policy* (Policy Press, 2004) 14.

<sup>41</sup> Jennifer Parks, ‘Lifting the Burden of Women’s Care Work: Should Robots Replace the ‘Human Touch’?’ (2010) 25 *Hypatia* 100.

because of the peculiar skills and virtues of receptivity and responsiveness that caring involves. They are, moreover, linked to the fact that care is asymmetrical in that, unless it is paid, it implies benefiting others and burdening oneself.<sup>42</sup>

While, therefore, it is correct to explore the ways in which being ‘a carer’ can be a source of power over the person ‘cared for’, it is important to recognise that caring relationships bring out and create a mutual vulnerability.

### *B Respect and Care*

Most care ethicists acknowledge that respect is an essential aspect of care. It involves being alert to what the other needs and responding to those needs appropriately. It is not about treating the other as an object, but recognising them as a fellow human being with whom one is in a relationship. Robin Dillon captures this with the word ‘attention’ and argues:

The term ‘care’ denotes here an epistemic attitude, understood as a moral ideal of attention: a commitment to attend, with intensely focused perception to all aspects of the irreducible particularity of individual human persons in their concrete contexts.<sup>43</sup>

There are four interconnected themes here that need to be unpacked.

First, respect involves recognising the fellow humanity in another. This involves not treating them in terms of categories or formulas, but recognising that they are a unique individual. This means that caring involves a degree of empathy and anticipation. These are needed to ensure that non-obvious needs are appreciated.

Second, respect involves listening to the other and ensuring, where possible, that there is consent. It involves accepting that what most people might want in a particular case is not necessarily what the individual necessarily wants. They should be treated as an individual, not just a person with a particular condition. Seeking out the particular needs and wishes of the other and seeking to meet them are an essential part of care.

Third, respect requires treating a person in a dignified way and respecting their innate humanity. This may involve, for example, ensuring more intimate aspects of care are done in private and showing due respect for their abilities. This is separate from the previous requirement, because there may be a case where a person lacks capacity and is not objecting to the form of treatment, but the treatment is done in public or in such a way as to undermine core notions of dignity.<sup>44</sup>

Fourth, respect requires an awareness of how the other person is experiencing the care. This involves interaction and engagement with the individual. Obviously care provided with no thought to the response of the person receiving it is in danger of objectifying the person receiving the care.<sup>45</sup>

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<sup>42</sup> Diemut Bubeck, *Care, Gender and Justice* (Clarendon Press, 1995) 149-50.

<sup>43</sup> Robin Dillon, ‘Respect and Care’ (1992) 22 *Canadian Journal of Philosophy* 105, 128.

<sup>44</sup> Charles Foster, *Human Dignity in Bioethics and the Law* (Hart, 2011) ch 2.

<sup>45</sup> Engster, above n 1, 55.

### C Interdependence

There is another important point here and that is the division of ‘carer’ is not only false because it imagines that one party to the relationship is the provider of the care, but it also overlooks the point that the ‘carer’ may themselves be receiving care from others. Notably, in the UK 378 000 carers are themselves registered as permanently sick or disabled according to official statistics.<sup>46</sup> Thus, it is more accurate to acknowledge the networks of care that we live in, rather than dividing us up into providers and recipients of care. All of us fall into both categories.

There is yet further significance in focusing on relationships of care. The discrimination against those seen as having a disability or infirmity can operate as a disadvantage to those in a relationship with them. Negative attitudes about disability are reflected in negative attitudes about care. As Bill Hughes and his colleagues put it:

...the parties involved in the caring relationship are perpetually invalidated because the value of care is measured against the autonomous adult male who neither requires nor delivers care. To be a carer or cared for – male or female, disabled or non-disabled in either role – is to be found wanting, to be other in relation to the masculine subject of modernity, to be reduced to ‘the other of the same’. Those who give and receive care are marginalized, ‘used and wasted’ bodies, existing, by and large, on the margins of what counts as the truly human community.<sup>47</sup>

I would go further and question whether even in our so-called prime we do have the kind of autonomy and capacity traditional liberalism claims for adults. My point is that we are *all* vulnerable.<sup>48</sup> We are all profoundly dependent on others for our physical and psychological wellbeing. Part of our vulnerability leads from our embodiment.<sup>49</sup> We like to present our bodies as self-contained and secure structures. In fact, our bodies are leaky and in a constant change of flux.<sup>50</sup> Our bodies are insecure and vulnerable. Our society has built up a wide range of structures and forms of assistance which disguise our vulnerability. Indeed, we are forced by a wide range of societal pressures to disguise or mitigate our vulnerability so that we can behave in an acceptable way in the public realm. In a powerful article, Kate Lindemann contrasts the emphasis that is paid to the accommodations for disabled people so as to minimise the impact of their disability, with the lack of appreciation of the similar accommodations for the able bodied:

Colleagues, professional staff members, and other adults are unconscious of the numerous accommodations that society provides to make their work and life style possible. ATM’s, extended hours in banks, shopping centres and medical offices, EZpass, newspaper kiosks, and elevators are all accommodations that make contemporary working life possible. There are entire industries devoted to

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<sup>46</sup> Carers UK, *Facts About Carers* (Carers UK, 2009).

<sup>47</sup> Bill Hughes et al, ‘Love’s Labours Lost? Feminism, the Disabled People’s Movement and an Ethic of Care’ (2005) 39 *Sociology* 259, 265.

<sup>48</sup> Martha Fineman, ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (2008) 20 *Yale Journal of Law and Feminism* 1.

<sup>49</sup> Groenhout, above n 1, 3.

<sup>50</sup> Jonathan Herring and P-L Chau, ‘My Body, Your Body, Our Bodies’ (2007) 15 *Medical Law Review* 54.

accommodating the needs of adult working people. Fast food, office lunch delivery, day time child care, respite care, car washing, personal care attendants, interpreters, house cleaning, and yard and lawn services are all occupations that provide services that make it possible for adults to hold full time jobs.<sup>51</sup>

We thus highlight the facilities used to deal with the vulnerabilities of others, while overlooking the accommodations 'we' need to deal with our vulnerabilities. Further, we readily class those who need care from others as vulnerable, without seeing the vulnerability that caring creates for the carer.<sup>52</sup>

The significance of the failure to acknowledge our common vulnerability is that, as Martha Fineman argues, we lose sight of the power and privilege that is used by some to disguise theirs:

When we only study the poor, the rich remain hidden and their advantages remain relatively unexamined, nestled in secure and private spaces, where there is no need for them or the state to justify or explain why they deserve the privilege of state protection. We need to excavate these privileged lives. While sometimes this will be a difficult and complex undertaking, there are certainly abundant records and instruments of privilege all around us that can be accessed relatively easily. These archives are located in corporate boardrooms and in the rules setting up or limiting state and national regulatory regimes. They can be gleaned from tax and probate codes, history books, literature, political theories, and of course, from the language and logic of the law.<sup>53</sup>

Kelly Fritsch has provided a powerful practical example of how in caring relationships individual identities become merged. In her sensitive analysis of the use of carers or attendants to facilitate and enable sexual encounters for disabled people she shows how the line between bodies in these cases is complex:

...experience a leaking of their identities, a mingling of their sexualities, and multiple intimate slippages of selves as the attendant participates in the daily work of feeding, bathing, shopping, facilitating sex, and numerous other activities. In the interaction between a disabled person and an attendant, both bodies extend into one another, displacing the limits of their assumedly contained sovereign selves.<sup>54</sup>

In summary, ethics of care criticises other general approaches to ethics as 'modelled on the experience of men in public life and in the marketplace'<sup>55</sup> and failing to reflect the life of most. While the marketplace model is based on assumptions of our independence and need to pursue our own goals, ethics of care has at its heart an acknowledgement of our vulnerability from which flows an acknowledgement of the importance of interdependency and care. The

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<sup>51</sup> Kate Lindemann, 'The Ethics of Receiving' (2003) 24 *Theoretical Medicine and Bioethics* 501, 502.

<sup>52</sup> Hughes et al, above n 48, 259.

<sup>53</sup> Martha Fineman, 'Equality: Still Illusive After All These Years' in Joanna Grossman and Linda McClain (eds), *Social Citizenship and Gender* (Cambridge University Press, 2010) 252.

<sup>54</sup> Kelly Fritsch, 'Intimate Assemblages: Disability, Intercorporeality, and the Labour of Attendant Care' (2010) 2 *Critical Disability Discourses* 1, 1.

<sup>55</sup> Held, above n 1, 23-24.

law and society should above all be seeking to uphold and maintain caring relationships. It is because we are, have been, and will be, dependent on others, that caring is so important.

There is an important uniting force between care ethics and disability studies. The model of independence, with linked themes of self-sufficiency and the importance of economic productivity can be used to sideline both disabled people and those in caring relationships. In her writing on the topic Christine Kelly has written how care can be a ‘complex form of oppression that affects both the recipients and providers of support’.<sup>56</sup> Downgrading care works to the disadvantage of disabled people. Downgrading disabled people impacts on those in relationship with them.

#### D *The Benefits of Vulnerability*

Dependency and vulnerability are commonly assumed to be bad things. David Archard, writing on childhood, has stated:

There may be features of childhood but not of adulthood which are valuable, such as innocence, wonder and trust. There may, correspondingly be features of adulthood but not childhood which are valuable, such as experience and independence. It is also evident that there may be features of childhood but not of adulthood which are not valuable, such as dependence and vulnerability.<sup>57</sup>

I think both of these views are profoundly mistaken. Vulnerability and dependence are not only inevitable parts of humanity, as argued above, they are to be greatly welcomed. They are virtues, not vices.

Self-reliance has become a dominant theme in social policy. Be it lone parents or care in the community, autonomy and independence have become key policy goals. But this ignores the fact that as humans we are interdependent.<sup>58</sup> No one can be truly independent. Hence, the UK Government’s aspiration in its latest document on care is utterly misguided: ‘Our vision is one that promotes people’s independence and wellbeing by enabling them to prevent or postpone the need for care and support.’<sup>59</sup>

The anti-vulnerability narrative tends to promote disablist approaches to the issue. As many writers from disability studies have written, there is great pressure on disabled people to be perceived as being independent and lacking vulnerability. Success for a person with a disability is measured by the extent to which they may be able to be (or present themselves as being) independent and autonomous – in short, to be ‘normal’.

Yet being vulnerable is an aspect of many of the things people value most in their lives. Relationships, intimacy, care – all of these things in their nature render us vulnerable. It is only by properly appreciating our vulnerable nature that the importance of human rights is

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<sup>56</sup> Christine Kelly, ‘Re/Moving Care from the Ontario Direct Funding Program: Altering Conversations among Disability and Feminist Scholars’ (2013) *Social Politics* forthcoming.

<sup>57</sup> David Archard, ‘Philosophical Perspectives on Childhood’ in Julia Fionda (ed), *Legal Concepts of Childhood* (Hart, 2001) 52.

<sup>58</sup> Susan Dodds, ‘Gender, Ageing, and Injustice: Social and Political Contexts of Bioethics’ (2005) 31 *Journal of Medical Ethics* 295.

<sup>59</sup> Her Majesty’s Government, *Caring for Our Future* (The Stationery Office, 2012) 18.

appreciated.<sup>60</sup> Similarly, dependency should not be something to be afraid of or ashamed of. Something has gone very wrong with our care of vulnerable older people when ‘not being a burden’ is reported as the main goal of their lives by patients living in nursing homes.<sup>61</sup> Dependency on others is an aspect of our humanity.

We need to recognise the benefits of vulnerability. Janine Wiles writes:

Vulnerability is often seen as fragility or weakness, but it may also be conceptualised as openness, susceptibility, and receptiveness. Ideas about vulnerability as inherent to the self and as formative might be usefully applied to the experiences of older care recipients. To experience and acknowledge one’s vulnerability may be a process of renegotiation of one’s sense of embodied self and relationships to people and places.<sup>62</sup>

There is one particular benefit of doing this. By emphasising the vulnerability of us this provides us with a powerful challenge to the disability/ability distinction. The disability critique of ethic of care seeks to find a way of empowering disabled people and giving them the tools to take control of their lives so that they can become ‘able-bodied’. But this is in danger of accepting a particular norm, one centred on independence. As Jayne Clapton puts it:

Such a construction, which privileges a particular understanding of personhood, assumes a prototypical disembodied person – that is, typically a male characterized by independence and the presence of rationality and reason; or in other words, that which constitutes, in the philosophical sense, ‘normal’.<sup>63</sup>

I would recommend that rather than challenging the disability/ability distinction by helping disabled people reach the able-bodied norm, we challenge it from the other direction. We need to acknowledge that we are all disabled.

Our universal disability reflects what Martha Fineman has argued: vulnerability is a ‘universal, inevitable, enduring aspect of the human condition’.<sup>64</sup> We are all limited by our bodies in different ways by what we can and cannot do. At different points in our lives, our bodies restrict us in different ways. In one sense at birth, we are all profoundly disabled and dependent on others. Even those in the ‘prime of health’ are dependent on others for services from public transport, to the supply of energy, to the provision of food.<sup>65</sup> We all have a range of limitations and need others and our community to meet our needs.

Rosemarie Garland-Thomson uses the term ‘misfits’ to capture the way disabled people are sidelined.<sup>66</sup> This is a helpful metaphor. It can be used to explain how at different points in lives and in different situations our bodies fit or fail to fit with the situation surrounding us.

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<sup>60</sup> Bryan Turner, *Vulnerability and Human Rights* (Pennsylvania State University Press, 2006) ch 2.

<sup>61</sup> Sabine Pleschberge, ‘Dignity and the Challenge of Dying in Nursing Homes: The Residents’ View’ (2007) 36 *Age and Ageing* 197.

<sup>62</sup> Janine Wiles, ‘Reflections on being a Recipient of Care: Vexing the Concept of Vulnerability’ (2011) 12 *Social and Cultural Geography* 573.

<sup>63</sup> Jayne Clapton, ‘Tragedy and Catastrophe: Contentious Discourses of Ethics and Disability’ (2003) 47 *Journal of Intellectual Disability Research* 540.

<sup>64</sup> Fineman, ‘The Vulnerable Subject’, above n 48, 1.

<sup>65</sup> Lindemann, above n 51, 501.

<sup>66</sup> Rosemarie Garland-Thomson, ‘Misfits: A Feminist Materialist Disability Concept’ (2011) 26 *Hypatia* 591.

Rather than stigmatising the ‘disabled’, we should recognise the ‘misfitedness’ that we all experience in different ways and at different times.<sup>67</sup> It invites society to think about what it does and does not provide to citizens. It would recognise the adaptability and resourcefulness used by ‘misfits’ and the way these are undeveloped in the fitting bodies.

I am not seeking to suggest that we are all vulnerable or disabled in the same way. We all have our unique weaknesses and strengths. Indeed our weaknesses can be strengths in some contexts, and weaknesses in others. However, we should emphasise the vulnerability we all have, the care we all receive and the care we all give. These caring relationships, however, cause disadvantages and we need to ensure that our social provision and legal responses ensure a fair distribution of the costs of caring relationships.

#### IV CONCLUSION

This article has examined the critique of care ethics offered by disability studies. This critique complains that the writing on care has focused on ‘carers’ and has not considered the position of those ‘cared for’, that the paternalism that can underpin care is too easily ignored, and that disabled people need empowering, not being rendered passive through care. These criticisms are to a large extent justified, especially in relation to some of the public campaigns mounted by organisations working to promote the interests of carers. However, these concerns do not undermine care ethics. They require us to emphasise that we should seek to promote caring relationships, not just carers. We should emphasise that respect is central to good care, and that, most importantly, in the caring relationships we are all in there is a merging of interests and selves. Vulnerabilities, care and identities become mutual and interdependent. We need to break down the division between the ‘carer’ and the ‘cared for’, between the ‘disabled’ and the ‘able-bodied’. Instead, we need to recognise our mutual vulnerability and need for care and ensure that there is a fair division of the burden and costs attached to caring relationships. As this article has sought to show, challenging attitudes towards disability and care should not be in opposition, but go hand in hand.

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<sup>67</sup> Ibid.