

DISABILITY AND CARE

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I. INTRODUCTION

This article will look at the surprising tensions between those who support disability rights and those who support rights for carers. It might be thought that such well-minded people would be in agreement, but there are certainly disputes between their camps. Some disability rights activists are critical of the concept of care because it posits the disabled person as passive and needing to be looked after. The cosy language around care overlooks the power that carers have over disabled people. By contrast, carers groups often emphasise the disadvantages they suffer and wish to emphasise the high level skills they possess. However, this can easily be seen as presenting disability as a ‘problem’ and one that causes disadvantage to others.

This paper will unpack that debate and explain the tensions between the concepts of disability and care. It will argue that this dispute can be overcome if we emphasise the importance of caring relationships, rather than separating the parties into “carers” and the “cared for”. In other words, care should be understood in a relational way.¹ Care should not be seen as something that is done by one person to another. Indeed, it is in the nature of caring relationships that the boundaries between the parties become blurred. The lines between one who is a carer and one who is cared for; those who are disabled, and those who are non-disabled, break down. With this approach, the tension between disability activists and carers activists can be mitigated. Further, we can recognise the need for all of us to receive and give care.

This article will start with the objections to the concept of care raised by disability activists, before exploring how supporters of ethics of care might respond.

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¹ Jonathan Herring, *Law and the Relational Self* (2019); Jonathan Herring, ‘Ethics of Care and Disability Rights: Complementary or Contradictory?’ in Loraine Gelsthorpe, Perveez Mody and Brian Sloan (eds), *Spaces of Care* (2019), from which this article draws.

II. THE DEFINITION OF DISABILITY

To understand the disability critique of care, it is necessary to approach the much-debated issue of the nature of disability. As is well known there are two contrasting models of disability: the individual and the social model;² while much recent work has been to find an approach which acknowledges elements of each.

A. THE MEDICAL MODEL OF DISABILITY

Under the medical model (sometimes called the individual model), disability is seen as a difference in a person's body or mind that distinguishes them from a "normal person" and causes them impaired functioning. The disadvantages that a person suffers under this model are seen to flow from their bodily difference.³ The response to disability under this model is to cure the defect in the body; mitigate its impact; or even prevent disabled people from being born in the first place.⁴ Therefore, under this model, significant power is given to the medical experts, for it is they who can recognise the "defect" and how best to "cure" or "mitigate" it. As Justin Haegele and Samuel Hodge⁵ explain:

"In the medical model, treatment for individuals with disabilities is geared toward eradicating the cause of or fixing the impairment Fixing is thought to be the best path toward function and independence, and those who may not want to be fixed are considered non-compliant or unmotivated This is best achieved by placing individuals with disabilities under direct authority of the medical profession in rehabilitation programs or institutional care."

B. THE SOCIAL MODEL OF DISABILITY

Under the social model, the difficulties that impact disabled people are located in society's failure to provide the necessary services, provisions and accommodations, rather than the differences in the body. This point can be made with an example. No one can by themselves jump or fly to the sixth floor of a building. If stairs are put in, this would enable some people to reach the sixth floor, but not others. If a lift is put in, that would enable more people to reach the sixth floor. If only a rope is provided, few will be able to do so. Who (if anyone) will

² Anita Ghai, *Rethinking Disability in India* (2015); Tom Shakespeare, *Disability Rights and Wrongs* (2006).

³ For a discussion and critique see Steven R. Smith, 'Social Justice and Disability: Competing Interpretations of the Medical and Social Models' in Kristjana Kristiansen, Simo Vehmas, Tom Shakespeare (eds) *Arguing About Disability* (2008).

⁴ Janet Radcliffe Richards, 'How Not to End Disability' (2002) 39 *San Diego Law Review* 693.

⁵ Justin Haegele and Samuel Hodge, 'Disability Discourse: Overview and Critiques of the Medical and Social Models' (2016) 68 *Quest* 193.

be en-abled or dis-abled to get to the sixth floor depends on the provisions provided. More generally, everyone needs provisions by society to meet their needs. While we tend to think of “disabled people” needing accommodations, in fact, everyone needs services from society (be it sewerage, water, shops, transport etc.). Society chooses which services are to be provided and how to provide them. These services meet the needs of some people but not of others. It is society, through these decisions, which determines which bodies are “disabled” and which are not. Indeed, supporters will see particular benefit in the terminology - “disabled person” because a person is disabled by the (lack of) societal provision. Society is “manufacturing disability”.⁶ The term disability is useful primarily to highlight which bodies are rendered disabled by the (lack of) societal provision.

The Union of Physically Impaired Against Segregation, 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.”⁷

This social model has become particularly influential in recent years, and is promoted by the Americans with Disabilities Act (ADA)⁸. It can also be seen in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).⁹

⁶ Angelica Guevara, ‘Ableness as Property’ (2020) 97 *Denver Law Review* 1.

⁷ Union of Physically Impaired Against Segregation, *Fundamental Principles of Disability* (1975).

⁸ Americans with Disabilities Act of 1990, Pub LNo 101-336, § 2, 104 Stat 328 (1991).

⁹ UN General Assembly, *United Nations Convention on the Rights of Persons with Disabilities* (2007).

C. COMBINED MODELS OF DISABILITY

It is becoming increasingly common to seek a middle road between the two approaches.¹⁰ For example, Myrian Winance¹¹ suggests we can,

“separate the deficiency (an individual biological characteristic) from the disability (a social reality, a position of exclusion defined in relation to the balance of power between people)... Disability is a social difference piled on top of a natural specificity.”

Typically, writers seeking a middle ground accept the force of the social model but argue that there comes a point at which the disadvantage a person faces cannot be met by societal provisions. To take an extreme example, a person in a Persistent Vegetative State suffers disadvantages that no amount of societal provision can meet. Further, to see the impact of disability as simply as a matter of social provision belies the fact that disability is experienced in the body of a disabled person. The disability is not simply something done to them by society, but is a bodily difference.¹² Recognising that the impact of disability is felt in the body as well as by the force of society, means that it is possible to acknowledge that disability is experienced differently by disabled people with the same impairment, according to identity and situation. As Michael Rembis states:

“Humans produce impairment through their actions (war, work and disease), and impairment is always influenced by race, gender, religion, sexuality and other markers of identity, as well as by material conditions and economic structures. Impairment must be considered within its particular social, cultural and historical context.”¹³

Elizabeth Barnes prefers to refer to a “difference”, rather than the term deficiency or impairment, as a term which does not indicate any judgment.¹⁴ She argues,

“Disability is . . . a neutral feature [that] is compatible with its being — in a restricted sense — something that’s bad for you. The same

¹⁰ Jonas-Sébastien Beaudry, ‘Theoretical Strategies to Define Disability’ in David T. Wasserman and Adam Cureton(eds), *The Oxford Handbook of Philosophy and Disability* (2020).

¹¹ Myrian Winance, ‘Rethinking Disability: Lessons from the Past, Questions for the Future. Contributions and Limits of the Social Model, the Sociology of Science and Technology, and the Ethics of Care’ (2016) 10 *European Journal of Disability Research* 99, 101.

¹² Simo Vehmas and Nick Watson, ‘Moral Wrongs, Disadvantages, and Disability: A Critique of Critical Disability Studies’(2014) 29 *Disability and Society* 638.

¹³ Michael Rembis, ‘Challenging the Impairment/Disability Divide: Disability History and the Social Model of Disability’ in Nick Watson and Simo Vehmas (eds), *Routledge Handbook of Disability Studies* (2019) 387.

¹⁴ Elizabeth Barnes, *The Minority Body: A Theory of Disability* (2016).

feature . . . that's bad for you with respect to some aspects of your life can be good for you with respect to other aspects of your life."¹⁵

This can capture the idea that for many "bodily differences" there are both advantages and disadvantages that come with them; as is true for standard bodily forms.¹⁶

It is not the aim of this article to resolve the debates between these different views, but to provide important background to the critique of care.¹⁷

III. THE DISABILITY RIGHTS CRITIQUE OF CARE

Critics of care from within disability rights tend to make two key points. The first is that the concept of care is tied in with the medical model of disability. The second is that the concept of care allows the "carer" to exercise power over a disabled person. They then promote the model of a personal attendant or assistant, which is seen to be preferable to a carer model. I will summarise these points before considering how an ethics of care might provide reconciliation.

A. CARE AND THE MEDICAL MODEL OF DISABILITY

Critics of the concept of care argue that it builds on an individual model of disability. Many definitions see an essential element of care being that it meets the "needs" of the person receiving care.¹⁸ This can be seen to be presenting the disabled body as having faults which a non-disabled carer can help with and bring the disabled person back to "the norm".

This problematic understanding of care is reinforced by the (understandable) campaigns by groups working for carers which emphasizes the burdens of care. To give one example, one survey of the literature on those caring for people with Alzheimer's disease states:

"Family and friends provide nearly three-quarters of all care for patients with Alzheimer's disease. This informal care results in significant burden to care givers. Care giver burden is the set of physical, psychological or emotional, social, and financial problems that family members may experience when caring for impaired older adults. Care givers of Alzheimer's disease patients report higher rates of physical

¹⁵ Ibid 79.

¹⁶ An obvious example might be autism where gifts of memory may be combined with difficulties in social interaction.

¹⁷ For further discussion see Shelley Tremain, Foucault and Feminist Philosophy of Disability (2017).

¹⁸ Jonathan Herring, *Caring and the Law* (2013).

symptoms, mortality, depression, and fatigue, as well as adverse effects on employment compared with those who are not care givers for Alzheimer's disease patients."¹⁹

Unintentionally, these kinds of comments imply that disability is “a problem”, for which carers pay the cost of solving. This goes against the social model of disability and the positive portrayals of disability mentioned above.²⁰ It also seems to draw a sharp binary distinction between “the carer” and the “cared for”.²¹

B. CARE AND POWER

Care literature often presents the practice of care in idealised terms. It is described as “the ultimate good”.²² Yet care ethics needs to acknowledge “the dark side of care”.²³ Of course, the literature highlights the dangers of abusive relationships and is clear that care ethics is not supporting any kind of relationship. Indeed, I have argued that care ethics gives us a particularly convincing case for arguing that abuse within intimate relationships is a serious wrong.²⁴ However, what is often left unmentioned is that “normal care” can involve the exercise of power. That there is a paternalistic edge that regularly accompanies care.²⁵ This is well captured by Richard Woods²⁶ who writes:

“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.”

Jan Morris²⁷ has argued that care itself is a form of oppression against disabled people:

“The only way to empower disabled people is to throw off the ideology of caring, which is a form of oppression and an expression of

¹⁹ Daniel Kaufer, Soo Borson, Peter Kershaw and Kay Sadik, ‘Reduction of Caregiver Burden in Alzheimer's Disease by Treatment with Galantamine’(2005) 10 *CNS Spectrums* 481, 484.

²⁰ Anita Silvers, ‘Philosophy and Disability: What Should Philosophy do?’ (2016) 93 *Res Philosophica* 843.

²¹ Margrit Shildrick, *Leaky Bodies and Boundaries* (2012).

²² Jonathan Herring, *Caring and the Law* (2013) ch 2.

²³ Michael Fine, *A Caring Society?: Care and the Dilemmas of Human Services in the 21st Century* (2007) 4.

²⁴ Jonathan Herring, *Domestic Abuse and Human Rights* (2020).

²⁵ Tom Shakespeare, *Help: Imagining Welfare* (2001) ch 2.

²⁶ Quoted Tom Shakespeare, *Help: Imagining Welfare* (2001) 63.

²⁷ Jan Morris, ‘Care of Empowerment: A Disability Rights Perspective’ (1997) 31 *Social Policy & Administration* 54.

prejudice. Empowerment means choice and control; it means that someone has the power to exert choice and therefore maximise control in their lives (always recognising that there are limits to how much control any of us have over what happens in our lives). Care – in the second half of the twentieth century – has come to mean not caring about someone but caring for in the sense of taking responsibility for. People who are said to need caring for are assumed to be unable to exert choice and control. One cannot, therefore, have care and empowerment, for it is the ideology and the practice of caring, which has led to the perception of disabled people as powerless.”

What these quotes capture is that receiving “care” can be experienced as an exercise of power. The “carer” identifies the need of the “cared for” and then decides how to meet it. It is the carer who is active, and the “cared for” who is passive.²⁸ At its worst, care can become abusive, as Christine Kelly²⁹ writes:

“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.”

But, at the heart of the challenge to the nature of care are more mundane ways that care can involve power. Julia Twigg³⁰ researched older people’s experiences of being bathed and highlights that well:

“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.”

This experience, of being silenced and rendered passive, reflects the wider range of ways that society marginalises and silences disabled people.³¹

²⁸ Bernhard Weicht, ‘Embracing Dependency: Rethinking (In)Dependence in the Discourse of Care’ (2010) 58 *Sociological Review* 205.

²⁹ Christine Kelly, ‘Making “Care” Accessible: Personal Assistance for Disabled People and the Politics of Language’ (2011) 31 *Critical Social Policy* 562, 565.

³⁰ Julia Twigg, *Bathing – the Body and Community Care* (2000) 180.

³¹ Anita Silvers, ‘Reconciling Equality to Difference: Caring (F) or Justice for People with Disabilities’ (1995) 10 *Hypatia* 30.

C. FROM CARE TO ASSISTANCE

Diemut Bubeck³² argues care involves,

“the meeting of needs of one person by another where face-to-face interaction between care and cared for is a crucial element of overall activity, and where the need is of such a nature that it cannot possibly be met by the person in need herself.”

In response to such a presentation of care and some of the points made above, some disability activists have argued we need to move away from the term care and recommended the concept of attendant services. Under such a model, the “consumer” (the disabled person) directs what the attendant is to do. The role of the attendant is to maximise the autonomy of the disabled person.³³

The reasoning behind this shift in terminology is that it alters the power dynamics. The concept of an attendant or a personal assistant indicates that it is the disabled person who directs the services. The attendant responds to the requests of the disabled person, rather than, under the traditional model of care, the carer being the one who determines what care the disabled person needs. The attendant model is said to promote empowerment, choice and control. Indeed, arguments favouring such an approach correspond more broadly with patients being “co-managers” of their health.³⁴

Having looked at the disability critique of care, we can now consider whether the ethics of care can respond to these challenges.

IV. RESPONSES OF CARE ETHICS

There is a substantial and rich literature on the ethics of care,³⁵ and it is not possible to do more than provide a very brief overview in the present paper. At its core is the claim that caring should be the most highly valued activity in society. As Eva Feder Kittay, Bruce Jennings and Angela Wasunna³⁶ put it:

³² Diemut Bubeck, *Care, Gender and Justice* (1995) 129.

³³ Centre for Independent Living in Toronto, cited in Christine Kelly, ‘Re/Moving Care from the Ontario Direct Funding Program: Altering Conversations among Disability and Feminist Scholars’ (2014) 21 *Social Politics* 124, 126.

³⁴ Eg Jonathan Herring, Kmw Fulford, Michael Dunn and Ashok Handa, ‘Elbow Room for Best Practice? Montgomery, Patients’ values, and Balanced Decision-Making in Person-Centred Clinical Care’ (2017) 25 *Medical Law Review* 582.

³⁵ Eg Carol Gilligan, ‘Moral Orientation and Moral Development’ in Eva Feder Kittay and Diana Meyers (eds), *Women and Moral Theory* (1987); Virginia Held, *The Ethics of Care: Personal, Political, and Global* (2006); Daniel Engster, *The Heart of Justice: Care Ethics and Political Theory* (2007); Jonathan Herring, *Caring and the Law* (2013).

³⁶ Eva Feder Kittay, Bruce Jennings, B., and Angela Wasunna, ‘Dependency, Difference and the Global Ethic of Longterm Care’ (2005) 13 *Journal of Political Philosophy* 433.

“People do not spring up from the soil like mushrooms. People produce people. People need to be cared for and nurtured throughout their lives by other people, at some times more urgently and more completely than at other times.”

One of the central roles of any state is to ensure that the essential needs of its citizens are met and care is required to meet those needs. Caring is often invisible in public policy and ethics when it should be at the heart of it. Joan Tronto³⁷ explains that the 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.”

In light of such comments, there ought to be some embarrassment within the ethics of the care community about the fact that the concept of care has generated some opposition from within the disability community. The problem is that many supporters of ethics of care literature appreciate the importance of care and are concerned about the social isolation of carers; the personal and economic disadvantage of carers; and the lack of recognition that carers are given in society. Too often, then ethics of care has focused on the perspective of the carer, rather than the disabled person. However, I do not think the disability critique requires an abandonment of the ethics of care. Indeed, a proper understanding of the ethics of care reveals tools to respond to the issues. There are two aspects of the ethics of care literature that need to be highlighted, in response to the critique of care.

A. CARING RELATIONSHIPS

Rather than care ethics promoting acts of care, it should promote caring relationships.³⁸ This shift in terminology is important because it dismantles the distinction between the “carer” and “cared for”. In caring relationships, there is giving and receiving; a mingling of bodies; a breaking down of boundaries. Caring relationships are multi-directional. That ‘care’ is not done as an abstract activity or task but is rather a part of the dynamic giving and taking of care.³⁹ Caring involves investment in another’s well-being. Good care involves

³⁷ Joan Tronto, *Moral Boundaries: A Political Argument for Ethic of Care* (1993) 103.

³⁸ Jonathan Herring, *Caring and the Law* (2013).

³⁹ Jasmyne Rockwell, ‘From Person-Centered to Relational Care: Expanding the Focus in Residential Care Facilities’ (2012) 55 *Journal of Gerontological Social Work* 3.

working together at a task. It involves talking through and reaching a consensual solution.⁴⁰

It recognises that we are all givers and receivers of care. The individual acts within a relationship are ‘embedded in long-term dyadic relationships’.⁴¹ Relationships which often have a shared life course and history. Relationships which are fluid and complex. In such a context, the pigeon holing of the parties into categories of carer and care receiver becomes artificial. As Clare Beckett⁴² 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”.

It is more accurate to acknowledge that we all live in networks of care and our roles shift- between the relationships and over time. So, we cannot be divided up into those who give and those who receive care.

One aspect of this way of looking at the issue is that all those involved in caring relationships suffer by virtue of the devaluing of care. It is not just “carers” who suffer as a result of the lack of respect for care and not just “disabled people” who suffer from the lack of social provision. Negative attitudes about disability are reflected in negative attitudes about care and vice versa. As Bill Hughes, Linda McKie, Debra Hopkins and Nick Watson⁴³ put it:

“[T]he 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.”

⁴⁰ Charlotte Clarke, Jane Wilcockson, Julie Watson, Heather Wilkinson, Sarah Keyes, Lindsey Kinnaird, and Toby Williamson, ‘Relational Care and Co-Operative Endeavour– Reshaping Dementia Care Through Participatory Secondary Data Analysis’ (2020) 19 *Dementia* 1151.

⁴¹ Mary Larkin and Alisoun Milne, ‘Carers and Empowerment in the UK: A Critical Reflection’ (2014) 13 *Social Policy and Society* 13, 26.

⁴² Clare Beckett, ‘Women, Disability, Care: Good Neighbours or Uneasy Bedfellows?’ (2007) 27 *Critical Social Policy* 360, 365.

⁴³ Bill Hughes, Linda McKie, Debra Hopkins and Nick Watson ‘Love’s Labours Lost? Feminism, the Disabled People’s Movement and an Ethic of Care’ (2005) 39 *Sociology* 259, 265.

This has the important consequence that we should not limit the concept of disability discrimination to those who themselves labelled disabled, but accept how discrimination against disability, impacts those in caring relationships.

Another important aspect of seeing care as a relationship is that it shows the futility of seeking to reduce care to a series of tasks. This occurs particularly when care is marketised. For example, in England, there has been a move towards giving disabled people a personal budget. An assessment is made of what tasks they need help doing and the amount of money needed to supply a carer for that task is determined. However, this misrepresents the nature of time in caring; the unpredictability of a caring relationship; being available as needed; for keeping apart; drawing together. All of this does not fit into a timesheet or a thirty-minute time slot.⁴⁴

This understanding of care as a relationship is important too in understanding dignity. As Linda Barclays argues “it is by virtue of standing in particular kinds of social relationships that we can say a person has dignity.”⁴⁵ Where a disabled person is reduced to being the mere recipient of care; or where an “attendant” is reduced to being a tool of a disabled person, dignity is lost. Where they relate together and work together as humans, dignity is found.

B. OVER-EMPHASISING AUTONOMY

A second important insight from care ethics is to challenge the assumption that the ideal person is marked by having full autonomy and independence; that we should be self-sufficient and be able to look after ourselves. This is presented in traditional-liberal thought as the ideal which is typical for people and is one which people should aspire to.⁴⁶ On that view, disabled people are to be pitied; they are dependent on others for help. They need care and interventions so that they can get as close to the autonomous, independent norm as possible.

Such an approach would promote the personal attendant/assistant model mentioned earlier, where the disabled person directs the assistant to do jobs they cannot do and so, as far as is possible, have the autonomy and freedom they would have without the disability. Judy Heumann,⁴⁷ one of the founders of the Independent Living Movement, writes:

⁴⁴ Jonathan Herring, ‘Personal Budgets’ in Theresa Feiler, Joshua Hordern and Andrew Papanikitas (eds), *Marketisation, Ethics and Healthcare: Policy, Practice and Moral Formation* (2018).

⁴⁵ Linda Barclay, ‘A Dignitarian Approach to Disability: From Moral Status to Social Status’ in Adam Cureton and David Wasserman (eds), *The Oxford Handbook of Philosophy and Disability* (2018).

⁴⁶ Ben Colburn, *Autonomy and Liberalism* (2010).

⁴⁷ Cited in Susan Stoddard, ‘Independent living: Concepts and Programs’ (1978) 3 *American Rehabilitation* 2.

“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.”

Many feminist ethics of care writers have challenged the assumption that autonomy and independence as the goals for anyone. Lorraine Code describes the model objected to:

“Autonomous man is—and should be—self-sufficient, independent, and self-reliant, a self-realizing individual who directs his efforts toward maximizing his personal gains. His independence is under constant threat from other (equally self-serving) individuals: hence he devises rules to protect himself from intrusion.”⁴⁸

This ideal which underpins the personal attendant model is misguided. First, it assumes an ability to make decisions and direct the services. It can only be 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 impossibility or a burden.

Second, “independent decision-making” is not what most people, whether disabled or not, want or engage in. Most people, when making decisions of any significance, will generally consult with friends and others. Decisions, particularly those which affect others, are typically made together. This is reflected in the evidence about how caring works too. Families discuss and make these decisions together. A dialogue is arranged, designed to deal with the different care needs of those involved.⁴⁹ This goes against the rationally driven autonomous man. It is through having deep caring relationships that our autonomy flourishes and not through having assistants whom we can direct.

Third, it is not just the mixing of autonomies that is required in care, but the breaking of bodily boundaries and identities. Kelly Fritsch⁵⁰ has provided a powerful practical example of how in caring relationships, individual identities merge. 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. The carer and the cared for,

⁴⁸ Lorraine Code, *What Can She Know? Feminist Theory and the Construction of Knowledge* (1991) 77.

⁴⁹ Caroline Glendinning, Wendy Mitchell, and Jenni Brooks, ‘Ambiguity in Practice? Carers’ Roles in Personalised Social Care in England’ (2015) 23 *Health and Social Care in the Community* 23-32.

⁵⁰ Kelly Fritsch, ‘Intimate Assemblages: Disability, Intercorporeality, and the Labour of Attendant Care’ (2011) 1 *Critical Disabilities Discourse* 2.

“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. ... The emphasis, then, is placed not on what you can do for me but rather what we can create together.”

The promotion of individual self-sufficiency and autonomy fails to reflect the true nature of care.

Fourth, and most significantly, it promotes a false image of what it is to have a flourishing life. An ideal life is not one marked by autonomy and independence. There are a host of other matters which are far more important than these. Eva Feder Kittay's daughter, Sessa, has cerebral palsy and has profound physical and intellectual impairment. However, Feder Kittay⁵¹ writes that Sessa possesses:

“[T]he most important faculties of all. The capacities for love and for happiness. These allow those of us who care for her, who love her, who have been entrusted with her well-being, to form deep and abiding attachments to her. Sessa's coin and currency is love. That is what she wishes to receive and that is what she reciprocates in spades.”

The ethics of care offers a powerful alternative to the autonomous model of human flourishing. The reality is that all humans are profoundly dependent on others for our physical and psychological well-being. Human beings are, in their nature, profoundly vulnerable.⁵² We like to present our bodies as self-contained and secure structures. In fact, our bodies are insecure and “leaky”.⁵³ Our society has built up a wide range of structures and forms of assistance which disguise our vulnerability. In a powerful article, Kate Lindemann⁵⁴ contrasts the emphasis that is paid to the accommodations for disabled people 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 lifestyle possible. ATM's, extended hours in banks,

⁵¹ Eva Feder Kittay 'Not my way, Sessa. Your Way. Slowly.' A Personal Narrative in Constance Mui and Julien Murphy (eds), *Gender Struggles: Practical Approaches to Contemporary Feminism (Feminist Constructions)* (2002)100.(Plz chk).

⁵² Jonathan Herring, *Vulnerable Adults and the Law* (2016).

⁵³ Margrit Shildrick, *Leaky Bodies and Boundaries: Feminism, Deconstruction, Bioethics* (2012).

⁵⁴ Kate Lindemann, 'The Ethics of Receiving' (2003) 24 *Theoretical Medicine and Bioethics* 502.

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 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.”

The significance of the failure to acknowledge our common vulnerability is that, I argue, we lose sight of the fact that some people have the power and privilege to mitigate their vulnerabilities and others do not.⁵⁵ This kind of approach can unite care ethics and disability studies. Both can challenge the ableist assumption that to be “able” is to be self-sufficient and economically productive. Instead, it promotes a new understanding of the self as “fundamentally relational” that is elaborated and evolves by and in care relationships.⁵⁶ Such an understanding will challenge the assumption about the normal body and the meaning of productive citizenship, which is harmful to both, the valuing of disability and care. As Rosemarie Garland-Thomson⁵⁷ argues:

“[D]isability is perhaps the essential characteristic of being human. The body is dynamic, constantly interactive with history and environment. We evolve into disability. Our bodies need care; we all need assistance to live. An equality model of feminist theory sometimes prizes individualistic autonomy as the key to women’s liberation. A feminist disability theory, however, suggests that we are better off learning to individually and collectively accommodate bodily limits and evolutions than trying to eliminate or deny them.”

Vulnerability and dependence are not only inevitable parts of humanity; they are also to be greatly welcomed. They are virtues, not vices. Self-reliance has become a dominant theme in social policy. But this ignores the fact that as humans, we are interdependent. No one can be truly independent.

The anti-vulnerability narrative tends to promote ableist 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

⁵⁵ Martha Fineman ‘The Vulnerable Subject: Anchoring Equality in the Human Condition’ (2008) 20 *Yale Journal of Law and Feminism* 23.

⁵⁶ Myriam Winance, A Damamme and Emmanuel Fillion ‘Thinking the Aid and Care Relationship from the Standpoint of Disability: Stakes and Ambiguities’ (2015) *European Journal of Disability Research* 9, 163.

⁵⁷ Rosemarie Garland-Thomson, ‘Integrating Disability, Transforming Feminist Theory’ (2002) 3 *Feminist Disability Studies* 21.

may be able to be (or present themselves as being) independent and autonomous - in short, to be “normal”. As Jayne Clapton⁵⁸ 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”.”

Whereas in fact, the innate vulnerability of us all brings great benefits. Janine Wiles⁵⁹ 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 re-negotiation of one’s sense of embodied self and relationships to people and places.”

This is not to suggest that we are all vulnerable or disabled in the same way. Each of us have our own weaknesses and strengths. Often the same characteristics can be a strength in some contexts and a weakness in others. However, we should emphasise the vulnerability we all have, the care we all receive and the care we all give. Thomas Hill⁶⁰ has discussed the importance of appreciation in relationships. This involves appreciating what is good about each other’s lives and being open to values and learning from them. This can be a danger in the traditional image of the carer as it imagines care as a one-way activity. But in caring relationships, each party can learn from and appreciate the differences of each other. However, these caring relationships, cause disadvantages, and we need to ensure that our social provision and legal responses ensure a fair distribution of the costs of caring relationships.

The ableist message that being vulnerable, or dependent is harmful, is an error. Our mutual vulnerability requires us to reach out to others to offer and receive help from them. We have to become open to others and our own needs. A recognition of our mutual vulnerability leads to empathy and understanding. It creates intimacy and trust. It compels us to focus on interactive, co-operative solutions to the issues we address. It encourages creativity in finding new ways of

⁵⁸ Jayne Clapton, ‘Tragedy and Catastrophe: Contentious Discourses of Ethics and Disability’ (2003) 47 *Journal of Intellectual Disability Research* 540.

⁵⁹ Janine Wiles, ‘Social and Cultural Geography Reflections on being a Recipient of Care: Vexing the Concept of Vulnerability’ (2011) 12 *Social and Cultural Geography* 541.

⁶⁰ Thomas E. Hill, ‘Ideals of Appreciation and Expressions of Respect’ in Adam Cureton and David Wasserman (eds), *The Oxford Handbook of Philosophy and Disability* (2019).

overcoming our human limitations and requires a desire to accept others as they are.⁶¹

V. CONCLUSION

This article has examined the critiques of the concept of care from disabilities studies. There is much justification in these critiques. Standard understandings of care have seen care as an activity and emphasised the importance of meeting the needs of the person “cared for”. These understandings have failed to acknowledge that “care” can be a cover for paternalism and involve the exercise of power. However, it has been argued that these critiques require a more nuanced understanding of care, as can be understood within the ethics of care. This means that the focus should be on caring relationships, rather than on the acts of care

Further, we must challenge the norm of the autonomous, independent person which underpins much thinking in this area. Instead, we should acknowledge that everyone is in their nature, vulnerable and in need of caring relationships. In 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”. We need not be embarrassed by our precious, leaky, interdependent bodies or try and disguise their nature. We should not strive to be self-sufficient or hyper-rational. There is no reason to be ashamed of the fact we need others and public bodies to meet our most basic needs. That is because that is what being human is all about. As Feder Kittay⁶² puts it “I am because we are”. It is in our joining together with our different bodies, minds and personalities that we can respond to the challenges we all face.

⁶¹ Eva Feder Kittay, ‘Care and Disability: Friends or Foes’ in Adam Cureton and David Wasserman (eds), *The Oxford Handbook of Philosophy and Disability* (2019).

⁶² Eva Feder Kittay, ‘Care and Disability: Friends or Foes’ in Adam Cureton and David Wasserman (eds), *The Oxford Handbook of Philosophy and Disability* (2019).