

## **“Vulnerability, Autonomy, Disability”**

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[Note: This is a shortened and sketchy version of a longer chapter]

A number of scholars have been talking about vulnerability lately, within feminist philosophy, bioethics, sociology, and legal theory. The current trend is to argue that, instead of being a negative state, to be remedied if at all possible, vulnerability is actually something more ambivalent. Recent work has called it an “ontological condition of human beings”, and an “openness to the world” which helps make relationships and commitments possible.

Some of the theorists who explore this reframing of vulnerability set it in opposition to autonomy, which is assumed to imply an atomistic individualism. I’ll say more about this shortly – I’m mostly thinking of Martha Fineman and Debra Bergoffen.

This strikes me as a lost opportunity, since autonomy has *also* been the subject of a reframing over the last two decades. Feminist work on “relational autonomy” explores the way that our self-determination – our ability to decide on and pursue our own values, goals, and commitments – is intertwined with our social and relational ties: our values, goals, and commitments are worked out in the context of relationships and our social environment and upbringing, and will play out in these contexts as well. The self of “self-determination” is, after all, a social and relational self.

Some of the work done on vulnerability, then, has begun to incorporate this more relational understanding of autonomy, such that vulnerability and autonomy are no longer quite antitheses to each other, but it’s still somewhat scattered. I’ll say more about this shortly, but the most explicit statement of this connection that I’ve come across so far is in one paragraph of a paper by Wendy Rogers, Catriona Mackenzie, and Susan Dodds, though to some extent it’s implied by recent work by Judith Butler and others.

The reason why it matters that we figure out the relationship of vulnerability and autonomy is that, on its own, vulnerability can be a risky concept, given the danger of paternalism. In discussing vulnerability as an universal ontological condition of all humanity, we risk glossing over the very real differences between different kinds of vulnerability.

While we all need help, as Jenny Morris points out, “to depend on others for assistance in intimate tasks is not the same as depending on a mechanic to service your car” (Morris 2001, 13). But this perspective, coming from disabled writers, is largely absent from the vulnerability literature, which alludes to disability without engaging disabled people (for the most part).

Carol Gill points out, “Because people with disabilities have had to fight tenaciously to counter stereotypes of weakness and incompetence, discussions of our vulnerability feel risky from the outset” (Gill 2006, 183). She describes how assumptions about her vulnerability within the medical setting are harmful: “The attitudes and actions surrounding me there tell me that I am too disabled

to live. Although I feel robust and even fairly healthy around people who are familiar with my way of life, in the hospital I am made to feel fragile, critical” (Gill 2006). Talking about vulnerability as a form of subjectivity without incorporating these kinds of experiences – as checks – seems problematic.

Still, vulnerability seems to have taken off as a research topic.

So, what *do* the pro-vulnerability, anti-autonomy folks want to get out of it? And is it a problem?

Martha Fineman is one of the best known of the current scholars working on vulnerability. Her 2008 article in the *Yale Journal of Law and Feminism*, “The Vulnerable Subject: Anchoring Equality in the Human Condition” is cited in pretty much all the other recent literature.

In this essay, Fineman criticizes the practice of basing political and legal theory around the “autonomous subject”, and argues that this autonomous subject be replaced by the “vulnerable subject.”

Fineman argues that formalized notions of equality do not do enough to address systematic and structural oppression, and that the identity groups currently recognized by the law by “traditional equal protection analyses” are both too broad and too narrow to do the kind of work they’re intended to do. They are too broad because they include many individuals who are still relatively privileged and have attained a high level of success; they are too narrow because they do not recognize “poverty, denial of dignity, and deprivation of basic social goods” amongst members in unprotected identity groups (Fineman 2008, 3-4). [Basically, poor white folks]

If, instead, we recognize the ways that all humans are vulnerable, it can be used to leverage arguments for greater state responsiveness the face of different needs. Instead of the autonomous subject, who is assumed to be self-sufficient unless he or she pleads otherwise, Fineman suggests the vulnerable subject, which calls attention to the need for responsive institutions, social systems, and the assets needed to develop resilience (Fineman 2008, 10-15).

[This is all laid out as well on the website for Emory’s “Vulnerability and the Human Condition” Interdisciplinary Initiative, which Fineman facilitates, and which holds regular speaker series and so forth on this topic.]

This work on vulnerability is a development of earlier work on dependency, in her 2004 book *The Autonomy Myth*, where she argued for recognizing interdependency over the ideology of autonomy. So, her criticisms of autonomy, and her use of “autonomy” to stand in for a particular ethos of the liberal, individualistic, atomistic, ideally self-sufficient, etc., person, is long-standing.

Given this opposition between the “vulnerable subject” and the “autonomous subject” that Fineman’s 2008 essay rests on, the final sentence of the essay bears examination: “We must begin to think of the state’s commitment to equality as one rooted in an understanding of vulnerability and dependency, recognizing that autonomy is not a naturally occurring characteristic of the human condition, but a product of social policy” (Fineman 2008, 23). Earlier in the essay, she discusses the development of the assets required for *resilience* (Fineman 2008, 13-15), but she does not discuss the production of autonomy.

As such, it is unclear whether the resilient, vulnerable subject could also be autonomous, on Fineman's account. Given a relational autonomy framework, this would be pretty straightforward, but Fineman doesn't take up the possibility of this way of looking at autonomy. This is a shame, since the first invocation of "relational autonomy" in the literature was *also* in the Yale Journal of Law and Feminism, in 1989, in an article by Jennifer Nedelsky, "Reconceiving Autonomy: Sources, Thoughts and Possibilities." In that article, Nedelsky argues the same point: that the traditional notion of autonomy as involving self-sufficient independence and boundaries against others is unhelpful. Instead of rejecting it, autonomy can and ought to be reframed around the idea that self-determination is consonant with the importance of the role of others in relation to that self. This allows its use in anti-oppression work and in advocacy. Since then, the literature on relational autonomy has grown significantly.

This does not prevent "Autonomy" from standing in for a nefarious liberal concept for Fineman, and the same problem crops up elsewhere. Debra Bergoffen posits a similar dichotomy between vulnerability and autonomy in her work on vulnerability and genocidal rape, most notably in her 2012 book, *Contesting the Politics of Genocidal Rape: Affirming the Dignity of the Vulnerable Body*. I list the whole title here because, as a colleague pointed out, the subtitle itself suggests the kind of tension that Bergoffen faces, between advocating for the centering of vulnerability within human experience (though her account is focused on the gendered nature of vulnerability), and taking up a heritage of notions about "dignity", which inevitably find autonomy intertwined within them. Lest we think Kant's marriage of dignity and (rational) autonomy is too far behind us, we still have it in the foundations of our current international system: the Preamble to the UN Declaration of Human Rights reads "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world."<sup>1</sup> Without naming autonomy as such, the concept of it is present beneath the surface of this invocation of dignity: compare especially Article 1: "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood." If we were to describe the things guaranteed by the declaration, we would most likely describe them in terms of autonomy. (And certainly Bergoffen argues that human rights discourse rests on the notion of autonomy – this is one of the things she wants to see changed).

Bergoffen associates "autonomy" (i.e., the named concept "autonomy") with liberal individualism and the myth or "fantasy" of invulnerability (Bergoffen 2012, 74). Like Fineman, she uses it as a stand-in for the collection of values, ideological norms, and political and legal assumptions that she wants to reshape. Despite this, however, she cannot quite do without it. She relies on a notion of "self determination" (particularly sexual self-determination) in her work. She stresses that we mustn't confuse "autonomy" with "self-determination" (Bergoffen 2012, 79-80),<sup>2</sup> but she doesn't define

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<sup>1</sup> <http://www.un.org/en/documents/udhr/>

<sup>2</sup> "The effects of establishing the human right to sexual self-determination are difficult to predict. If the idea of self-determination is allowed to slide into the idea of autonomy, creating a right to sexual self-determination may have little effect on the autonomous subject's place in human rights discourses. Insofar as the right to sexual self-determination directs us to think of the self as existing in relationship with and vulnerable to others, however, it may get us to reassess our love affair with the vulnerable subject. If the newly created right to sexual self-determination is read as a challenge to the way that we have read rights as inhering within individuals rather than as existing between them, it will inaugurate a paradigm shift where the subject of rights, instead of being understood in terms of the first person singular imaginary autonomous "I," will be understood in terms of the first person plural corporeal, sexed, intersubjective and vulnerable "we".

what “self-determination” is, if it isn’t autonomy. If we were to investigate what she wants self-determination to do, if we didn’t know that she wanted to avoid the word “autonomy,” we would certainly invoke “autonomy,” much as we would for the UN Declaration.

The reason that autonomy – in whatever guise, under whatever name – keeps resurfacing is that it speaks to something that is important to us.

Remember the earlier quotations from Carol Gill – “The attitudes and actions surrounding me there tell me that I am too disabled to live ... I am made to feel fragile, critical.” In this kind of context, talking about how her vulnerability makes her more responsive and open to the world, per Fineman, isn’t helpful. What is needed is a notion of respect for autonomy, the kind of autonomy involved in respecting patients’ decisions, respecting that they know what their bodies are like on a day-to-day basis.

Losing the dimension of autonomy risks a kind of overgeneralized concept of vulnerability. Many of the origins of the disability rights movement involve calls for independence, self-determination. In the US, the Independent Living Movement, and in the UK, UPIAS (Union of the Physically Impaired Against Segregation), argued for greater control over their lives, *and* to have the resources to make that possible. Given the need for both, a kind of pure, self-sufficient version of autonomy is off the table, which forces from the get-go a more interesting version of it (as can be seen from discussions of ‘independence’ vs. ‘interdependence.’). [This is not to say that it’s simple, and that there aren’t sometimes hierarchical divisions between people who are more or less ‘independent’ – the ‘able-disabled’ – our societal norms about independence run deep]

Still, it forces a conversation where autonomy is *already* something that involves negotiating help from others. And in a situation of receiving help and care, we need a concept of autonomy to make sure that the person being cared for still has agency, self-determination, doesn’t need to sign those over to receive help.

Although it’s not yet as widely cited as Fineman’s and Bergoffen’s work, a relatively recent article in feminist bioethics by Wendy Rogers, Catriona Mackenzie and Susan Dodds makes some useful advances. They provide a helpful taxonomy of vulnerability (Rogers, Mackenzie and Dodds 2011, 24-25]):

1. “*Inherent* vulnerability refers to those sources of vulnerability that are inherent to the human condition and that arise from our corporeality, our neediness, our dependence on others, and our affective and social natures.” (24) This will vary depending on factors such as age, health status, resilience, social support, and so forth.
2. *Situational* vulnerability is “context-specific, and that is caused or exacerbated by the personal, social, political, economic, or environmental situation of a person or social group.” (24) It may be temporary or chronic.
3. *Pathogenic* vulnerability is generated by harmful responses to vulnerability, and may either exacerbate that vulnerability or create new vulnerability. Sources can include “morally dysfunctional interpersonal and social relationships characterized by disrespect, prejudice, or abuse, or by sociopolitical situations characterized by oppression, domination, repression, injustice, persecution, or political violence ... Other forms of pathogenic vulnerability arise when social policy interventions aimed to ameliorate inherent or situational vulnerability have the paradoxical effect of increasing vulnerability” (25)

In addition to this, they also discuss the importance of respecting autonomy. They note that this is often overlooked in discussions of vulnerability, risking an unwarranted paternalism (22-23).

This recognition of the risk of paternalism is important. Respect for autonomy is one of the core values of bioethics, and so it seems surprising that paternalism would be a risk. Alicia Ouellette's *Bioethics and Disability*, however, traces a number of the ways in which bioethicists and disability rights activists come into conflict; one of these is the suspicion from disabled activists who are concerned that within bioethics they are *solely* considered vulnerable, *solely* considered to be suffering, and that when cases go to court, courts have adopted an assumption about the tragedy of disability (Ouellette 2011, 57-66). This diminishes the opportunity to understand a life with disability as being a flourishing one, an autonomous one in its own right. [I'm massively simplifying what's a contentious issue, but pointing toward the particular importance of concepts of autonomy that work with the experience of disability].

For Rogers, Mackenzie, and Dodds, a recognition of vulnerability works together with respect for others' autonomy; they argue that "it is important to stress that vulnerability is an ontological condition of our humanity is because it encourages responses to 'more than ordinary vulnerability' that are based in a sense of solidarity, as distinct from paternalistic forms of intervention" (23).

In a related article on research ethics, Rogers, Dodds and Lange note that "researchers have a duty to foster the autonomy of vulnerable participants for instrumental reasons: autonomous individuals are usually more resilient than those whose agency is weakened" (Lange, Rogers, and Dodds 2013, 337). They go on to point out that "Autonomy is not only a guard against the powerlessness and despair that can fuel a vicious cycle of ever-increasing vulnerability. On our account, it is also an intrinsically valuable aspect of human life" (Lange et al 2013, 337).

Rogers, Mackenzie and Dodds then name relational autonomy, in one paragraph of their 2011 article, as being the best approach "to reconciling autonomy with the normative obligations arising from vulnerability," noting that "this approach to autonomy is thus premised on the fact of our inescapable dependency on, and hence vulnerability to, others" and is attuned to the way obligations may extend further "to promote the autonomy of persons who are more than ordinarily vulnerable" (Rogers, Mackenzie and Dodds, 2011, 23-24).

Asserting both autonomy and vulnerability at the same time helps guard against the temptation to paternalism. We can be both autonomous and vulnerable at the same time; we're not *just* vulnerable, nor are we *just* autonomous. We need concepts of autonomy and vulnerability that can make this understandable to us, to help us avoid either/or thinking. These can then lead to productive work on what promotes autonomy competency, resiliency, and other skills, as opposed to getting stuck in the dichotomy of the Autonomous Vs. Vulnerable subject.

This seems a good start, but I want to close today by pushing things a bit farther, and considering a little more what Fineman and Bergoffen are doing. For them, it is not *just* that vulnerability is universal, and thus that it provides a ground of solidarity. The fact of, *and* the recognition of, vulnerability both seem to provide a way of looking at the world that has its own value. This has been explored of late by Adriana Cavarero, Judith Butler, and Erinn Gilson (and I can say more about this during the question period if desired.) This work does not fully address the differential nature of vulnerability for different kinds of agents, but is still a good start.

It's worth asking what work these suggestions about vulnerability might do for us: to whom is it *news* that we're vulnerable? Kate Kaul writes of Fineman's proposals about universal vulnerability, "the force of this concept, its radical possibility, is in the shift to where it is most counter-intuitive—in the vulnerability of subjects whose subjectivity has never, as such, been challenged or open to question" (Kaul 2013, 104).

I think this makes sense. But it raises the question of what the relationship between vulnerability and autonomy is like for those for whom it's no longer radical, for whom the experience of this tension is just part of the everyday practice of negotiating the world. Work on vulnerability and autonomy should incorporate the standpoint of those about whom we have made the most assumptions.

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