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WHY BIOETHICS NEEDS A CONCEPT OF VULNERABILITY

WENDY ROGERS, CATRIONA MACKENZIE, AND SUSAN DODDS

Abstract

Concern for human vulnerability seems to be at the heart of bioethical inquiry, but the concept of vulnerability is under-theorized in the bioethical literature. The aim of this article is to show why bioethics needs an adequately theorized and nuanced conception of vulnerability. We first review approaches to vulnerability in research ethics and public health ethics, and show that the bioethical literature associates vulnerability with risk of harm and exploitation, and limited capacity for autonomy. We identify some of the challenges emerging from this literature: in particular, how to reconcile universal human vulnerability with a context-sensitive analysis of specific kinds and sources of vulnerability; and how to reconcile obligations to protect vulnerable persons with obligations to respect autonomy. We then briefly survey some of the theoretical resources available within the philosophical literature to address these challenges, and to assist in understanding the conceptual connections between vulnerability and related concepts such as harm, exploitation, needs, and autonomy. We also sketch out a taxonomy of sources and kinds of vulnerability. Finally, we consider the implications for policy evaluation of making vulnerability an explicit and central focus of bioethics. Our investigation is in the form of a broad survey motivating a research agenda rather than a detailed analysis.

Introduction

Vulnerability is often defined as being at increased risk of harm, and/or having a decreased capacity to protect oneself from harm. Bioethics frequently addresses people's risk of harm to health, to well-being or to autonomy, and so concern for human vulnerability is ubiquitous in bioethical discussion. Common approaches in bioethics, such as principlism, ethics of care, virtue ethics, and so forth, all focus upon potential harms incurred by practices such as health care or participation in research, and try to determine the moral responsibilities and duties of all involved. Vulnerability appears to be at the heart of bioethics. But if this is the case, then we need an adequately theorized conception of vulnerability that can be used to assess or justify the interventions and practices invoked in the name of protecting the vulnerable.

How is human vulnerability to be understood? On one hand, all human life is conditioned by vulnerability, as a result of our embodied, finite, and socially contingent existence. Vulnerability is thus an ontological condition of our humanity (Fineman 2008; Hoffmaster 2006; MacIntyre 1999; Ricoeur 2007; Turner 2006). On the other hand, we use the term to pick out greater than ordinary vulnerability, recognizing that people vary in their exposure to risk and in the resources at their command to counter such risks. To those so identified, we seem to owe specific moral obligations and greater duties of justice. As such, vulnerability is universal; at the same time, many vulnerabilities are contextdependent and demand ethical responses because of their significance within a particular setting (Rendtorff 2002).

Vulnerability arises from many sources: biological, social, political, environmental, and cultural. Some vulnerabilities, such as those related to embodiment, are unavoidable (we all bleed when cut), while others, such as those related to lack of access to health care, may be the result of unjust social arrangements. Identifying the different sources of vulnerability and the different ways in which vulnerability is realized will help to inform appropriate moral responses to human vulnerability. Careful articulation of the concept of vulnerability will also assist in ensuring that responses do not err in being too narrow (failing to recognize a source of vulnerability that merits response) or too broad (misidentifying a person or group as especially vulnerable, leading to paternalistic protections).

Finally, an adequate conception of vulnerability will not be restricted to protecting against harm, but may attend to the ways in which the development of capacities for resilience and the social conditions for promoting agency and autonomy constitute appropriate responses to vulnerability. If vulnerability arises from preventable causes, perhaps there are important connections between vulnerability, autonomy, and justice that ground more stringent obligations to the vulnerable than previously articulated.

Our approach is first to review the way that the concept of vulnerability has been understood in bioethics, specifically in research ethics and public health ethics, and to show that the bioethical literature associates vulnerability with risk of harm and exploitation, and limited capacity for autonomy. We argue that the concept is playing an important role in bioethical discourse, but that it is undertheorized and that, given vulnerability's central role in bioethics, we need a welldeveloped account of the concept. Second, we briefly survey some of the theoretical resources available within the philosophical literature to assist in developing such an account. Our aim in this section is not to develop a theory of vulnerability, but to outline the broad parameters of such a theory by providing a preliminary sketch of the conceptual connections between vulnerability and related concepts such as harm, exploitation, needs, and autonomy. In this section, we also identify some of the challenges that must be met by an adequate philosophical theory of vulnerability and sketch out a taxonomy of sources and kinds of vulnerability. Finally, we consider the implications for policy evaluation of making vulnerability an explicit and central focus of bioethics. Our investigation is in the form of a broad survey motivating a research agenda rather than a detailed analysis.

Section 1: Vulnerability and bioethics

Vulnerability is central to bioethics. Indeed, much of the motivating force of bioethics lies in recognition of the vulnerability of the sick, the dependent, those with disabilities, participants in research, and so forth. Use of the descriptor *vulnerable* has become ubiquitous (Hurst 2008), to the point that its utility has been challenged (Hurst 2008; Levine et al. 2004; Luna 2009; Macklin 2003; Schroeder and Gefenas 2009). We believe that the notion of vulnerability captures something morally important for bioethics about features of people and their situations, and that vulnerability requires some kind of moral response, but at present, the concept is under-theorized. Significant ambiguities and tensions in the way that the term *vulnerability* is understood and used in bioethics lead to problems of paternalism and overprotection of those deemed vulnerable, and neglect of those who are vulnerable in ways not identified by current accounts. Developing a robust and nuanced account of vulnerability in bioethics is necessary to allow us to identify sources of vulnerability and to determine

just who is vulnerable, be this at the individual, group, or population level; to ground duties such as protection to those who are vulnerable; and to recognize the circumstances in which interventions to ameliorate vulnerability are warranted.

Within bioethics, the concept of vulnerability has been most extensively discussed in research ethics and to a lesser extent public health ethics. This section therefore focuses upon the ways in which vulnerability is understood in these two areas of bioethics. Whilst vulnerability did not emerge explicitly as a key concept in the earliest bioethics literature, documents such as the Nuremberg Code and the Declaration of Helsinki were clearly aimed at providing protection to individuals who were vulnerable to harms incurred through participation in research. These documents mandated informed consent as the major protection against research-related harms, thereby informing subsequent understandings of vulnerability within bioethics more broadly. The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979) further developed the informed-consent approach to protecting research participants. However, as well as mandating informed consent for research participants, the Belmont Report distinguished vulnerable groups ("such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized" [12]) as warranting special attention, identified their potentially limited capacity to give consent, and highlighted the need for protection against the possible dangers of being involved in research. This created a dual approach to, and confusion about, vulnerability in research that continues to permeate the literature. This confusion stems from coupling the general claim that all research participants need protections, thereby implying that there are potential harms to which all participants are vulnerable (remedied by informed consent), with the more specific claim that some participants are more vulnerable than others, and to these especially vulnerable participants, additional duties are owed in relation to protection from exploitation and other harms. However, the relationship between universal and special vulnerability remains little examined, and designation as especially vulnerable opens the way for unwarranted paternalism.

In identifying certain groups as vulnerable, the Belmont Report used what has come to be known as the labeling approach, in which individuals or groups are labeled as vulnerable according to the presence or absence of particular characteristics (Luna 2009). In Belmont, there are at least three characteristics that identify members of the nominated groups as vulnerable. These are lack of capacity to consent to research; increased susceptibility to coercion or exploitation; and increased risk of harms (e.g., that which is associated with serious ill health). The relations between these characteristics are not further explained in the report; however, Nickel argues that there are two overlapping senses of vulnerability at work in the *Belmont Report*. The first relates to capacity to give autonomous informed consent, while the second concerns two aspects of fairness: 1) the unfair burden of research participation that may fall to disadvantaged or dependent groups who lack the power to refuse participation; and 2) the unfair distribution of the benefits of research, and in particular, the injustices that arise from exclusion from research (Nickel 2006, 248). While *Belmont* recommended that the vulnerable be excluded from research, Nickel sees exclusion as a potential injustice, and looks to accounts of benefit sharing rather than informed consent to remedy this injustice.

Critics of the labeling approach have argued that it is both too narrow and too broad (Levine et al. 2004; Nickel 2006). It is too narrow because it reduces vulnerability to questions of competence to give informed consent to research (Bielby 2008), making the point of ethical review to identify all of the factors that might constrain the capacity for consent. On this model, protection of the (incompetent) vulnerable is achieved by improving informed-consent procedures; if this is not possible, participants deemed vulnerable are excluded from research altogether. This approach risks being unduly paternalistic, and can lead to the exclusion of significant groups of people from research, including children, people with mental illnesses, pregnant women, or the elderly. In turn, this leads to inadequate information about therapeutics for individuals and groups so excluded, thereby compromising their health care (Lyerly et al. 2008; Rogers and Ballantyne 2009). The restrictive conception of vulnerability as incapacity to give informed consent also fails to address the full range of moral issues raised by vulnerability, such as susceptibility to exploitation (Macklin 2003), and, as Levine et al. (2004) have argued, a focus on informed consent will not provide protections against factors such as dangerous protocols, researchers with conflicts of interest, or dysfunctional institutions, all of which make participants vulnerable by increasing their risk of harm.

A second set of criticisms relates to what is seen as an over-inclusive approach to vulnerability, expanding the category to such an extent that nearly everyone has been identified and labeled as "vulnerable" (Hurst 2008; Luna 2009). This blanket approach renders the notion of vulnerability potentially vacuous and of limited use in responding to specific vulnerabilities in research,

because it obscures rather than enables the identification of the context-specific needs of particular groups or individuals within those populations (Levine et al. 2004; Luna 2009). The "everyone is vulnerable" approach dulls our responses to particular vulnerabilities, fails to account for context-specific harms, and can lead to discrimination and stereotyping of whole groups as incapable of caring for their own needs or of being self-determining. This finding in turn can then be used to justify unwarranted and unjust paternalistic responses (Dodds 2007; Ho 2008).

In contrast to the labeling approach, analytic approaches to vulnerability in research ethics have attempted to identify sources of vulnerability in order to assess their impact and develop remedies. Kipnis provides an early analytic account in which he identifies seven potential sources of vulnerability, understood as "a certain precariousness" that leaves the person open to being harmed or being taken advantage of by researchers (2003, 108). Despite identifying a range of sources of vulnerability, Kipnis argues for informed consent as the remedy, thereby aligning his response with the narrow labeling approach discussed above.

Hurst (2008) proposes a wider range of remedies to ameliorate the vulnerability of research participants. In her view, vulnerability does not generate specific moral obligations. Nevertheless the concept serves a useful purpose in directing attention to potential wrongs (e.g., being at greater risk for breach of confidentiality, or being denied the benefits accruing from the research) and in identifying who owes which duties in relation to avoiding these wrongs. The aim of her approach is to guide research ethics committees in both identifying and minimizing potential wrongs to the vulnerable so defined.2

These accounts consider both the sources and impact of vulnerability within research and hence provide a more nuanced understanding than the labeling approach, but do not provide a more comprehensive analysis that can ground our understanding of vulnerability beyond the research ethics setting. Likewise Luna (2009), in her insightful account of layers of vulnerability, also limits her investigation to research ethics.

In summary, while there has been considerable discussion of vulnerability in research, we lack a broader analysis that can link sources of vulnerability with our obligations to the vulnerable, and identify the circumstances and nature of warranted interventions that avoid both stereotyping and paternalism. In particular, the relations between respect for autonomy, the demands of justice, and vulnerability remain opaque.

If research ethics has been concerned with the connections between vulnerability and respect for autonomy via its focus on consent, within public health, ethical attention has turned to questions of justice in relation to the vulnerable. The late twentieth century saw a significant change in the philosophical orientation of public health. In 1986, the *Ottawa Charter* articulated a positive view of health in contrast to the previous disease-eradicating view that had dominated public health. The "new public health" that emerged was concerned with the health effects of factors such as social supports, behavior, environment, lifestyle, and social capital (known as the social determinants of health). A holistic view of health as a state of well-being rather than the mere absence of disease (Baume 1998) has led to new ideas about vulnerability to ill health.

Within public health practice, vulnerable populations have been defined as "social groups who have an increased relative risk or susceptibility to adverse health outcomes" (Flaskerud and Winslow 1998, 70). The particular disadvantages that lead to increased risk of ill health may vary according to situation, but there is some consensus about the groups who are at high risk of suffering poor physical, psychological, or social health compared with those who are not members of these groups. Vulnerable populations have been defined as those who, because of "financial circumstances or place of residence; health, age or functional or developmental status; ability to communicate effectively; presence of chronic or terminal illness or disability; or personal characteristics," are unable to safeguard their own needs and interests adequately (Agency for Healthcare Research and Quality 1999, cited in Brock 2002a, 283). We might think of these risk factors as individual sources of vulnerability, or as potential layers, as per Luna's descriptions of vulnerability in research ethics (Luna 2009).

There seem to be two different but overlapping sources of vulnerability (to poor health outcomes) identified within public health. First, vulnerability serves as a marker for disadvantage. We know from the literature on the social determinants of health that many kinds of deprivation and disadvantage—economic, educational, financial, occupational, social—are associated with poor health status. In this sense, vulnerability is useful shorthand for describing individuals, groups, or populations who suffer deprivation related to the social determinants of health, making them at higher risk of poor health. The second way in which vulnerability is used in the public health literature is to refer to those who already have some form of ill health that increases their risk of further ill health. Having a chronic illness such as diabetes or depression creates dependence upon medication and need for health care, with attendant increased risks of further

morbidity and so on. These two types of vulnerabilities are distinct but often coexist and compound each other through complex interrelationships in vicious cycles. For example, Aboriginal and Torres Strait Islander peoples in Australia are vulnerable in both of these senses—to ill health secondary to a long history of dispossession, poverty, and discrimination, and through ill health to ongoing cycles of disability, poverty, and premature death.

The nascent field of public health ethics (Bayer and Fairchild 2004; Baylis et al. 2008; Beauchamp and Steinbock 1999; Jennings et al. 2003; Powers and Faden 2006; Rogers 2006; Thomas et al. 2002) has taken these issues seriously. While there is no one dominant account of public health ethics in the literature, most scholars take a broadly social justice approach in which the duty to promote positive health outcomes is tempered by a commitment to identifying and giving priority to those whose ill health is the result of systematic social disadvantage (Baylis et al. 2008; Powers and Faden 2006). Brock articulates this position most explicitly, arguing that priority for worse-off groups is "the most plausible ethical framework for considering the claims of vulnerable populations" (2002b, 362–72). He justifies this claim in two ways, one related to the greater relative improvement in health garnered by directing resources to the worse-off, and the second related to justice. Brock argues that those who are vulnerable because of conditions that themselves constitute an injustice (for example poverty, homelessness, lack of education) and whose subsequent poor health further compounds the initial injustice, have a prior claim on resources compared with those whose ill health cannot be attributed to the actions of others or society, such as those with genetic disease, random accidents, and the like. While there are problems with this account (such as the difficulty of trying to distinguish the inevitably blurred boundaries between voluntary and involuntary behaviors), Brock's arguments for priority to the worse-off do represent an explicit attempt to spell out justice-based duties owed to the vulnerable. Other authors have been less explicit (vulnerability remains a background assumption in Powers and Faden's work, for example); and we lack an account that links Brock's justice-based claim to autonomy, exploitation, or a more complete account of vulnerability.

This brief survey shows that explicit links have been made between vulnerability and justice in public health ethics. Various types of vulnerability have been described, but as with research ethics, the definitions are largely descriptive and list-like rather than conceptual; there is a tendency to label, with the attendant risks of discrimination and paternalism; and there is no comprehensive account of sources of vulnerability or corresponding responsibilities owed to the vulnerable. Thus in bioethics we are at an impasse: how can we usefully identify the vulnerable and respond to their needs in morally defensible ways when it is not even clear just who they are or what they are owed? In the following section, we turn to the resources of moral philosophy to investigate whether these ambiguities and tensions arise from philosophical accounts of vulnerability, and to suggest directions for a more detailed and nuanced account of vulnerability than currently exists.

Section 2: Philosophical approaches to vulnerability

A philosophical theory of vulnerability must address the following questions: What is vulnerability? Why does vulnerability give rise to moral obligations and duties of justice?3 And what specific obligations and duties of justice are owed to persons who are "more than ordinarily vulnerable" (Sellman 2005)? A philosophical theory of vulnerability must also be able to respond to the two challenges identified in the previous section: how to reconcile a universal claim about ontological human vulnerability with a context-sensitive analysis of specific kinds and sources of vulnerability; and how to reconcile obligations to protect the vulnerable with obligations to respect autonomy. We do not think any extant philosophical theory satisfactorily addresses all these issues, but a number of theories provide useful conceptual resources for beginning to address them. In this section, we briefly discuss some of these theories. In doing so, we sketch out some of the conceptual connections that a fully developed theory of vulnerability will need to articulate between vulnerability and the concepts of harm, exploitation, needs, autonomy, and justice. We also outline a taxonomy of different kinds and sources of vulnerability, which we think is helpful in further specifying the layered approach to vulnerability advocated by Luna (2009).

Theorists such as Fineman (2008), Hoffmaster (2006), MacIntyre (1999), Ricoeur (2007), and Turner (2006), who understand vulnerability as an ontological condition of our humanity, link the concept of vulnerability to its derivation from the Latin word *vulnus*, meaning "wound," and to the capacity to suffer which is inherent to human embodiment. It is because we are embodied that human beings have "an organic propensity to disease and sickness, that death and dying are inescapable, and that aging bodies are subject to impairment and disability" (Turner 2006, 29). These theorists also link our corporeal vulnerability to the inherent sociality of human life: as embodied, social beings, we are both dependent on the care and support of other people—to varying degrees at various points in our lives—and vulnerable to the actions of others. We think

these theorists are right to emphasize the universal dimensions of vulnerability and to ground vulnerability in human embodiment, sociality, and dependency. What needs to be explained, however, is why universal vulnerability generates obligations, what specific obligations it entails, and why we have particular obligations to persons who are more than ordinarily vulnerable.

Goodin's important book, *Protecting the Vulnerable* (1985), develops a consequentialist theory of vulnerability that aims specifically to answer these questions. Goodin analyzes vulnerability in terms of harm: to be vulnerable is to be susceptible to harm to one's interests. He also understands vulnerability as essentially relational: one is vulnerable to particular agents with respect to particular sorts of threats to one's interests (112). It is because vulnerability is essentially relational that another person's vulnerability gives rise to special responsibilities on the part of those to whom she is vulnerable. This is Goodin's "principle of protecting the vulnerable" (PPV): that we have an obligation to act so as to prevent harms to, or protect the interests of, those who are especially vulnerable to our actions and choices.

PPV is grounded in the claim that vulnerability is the source of moral obligation. In Goodin's view, most of our fundamental duties and responsibilities arise from relationships of dependency and interdependency that are not chosen: "duties and responsibilities are not necessarily (or even characteristically) things that you deserve. More often than not, they are things that just happen to you" (133). Familial duties and responsibilities are paradigmatic here, but Goodin argues that many other relationships are less voluntary than we often assume, such as those between friends, health-care professionals and their patients, teachers and students, and employers and employees. Goodin thus rejects contractualist and voluntarist models of obligation. What generates obligations, in his view, is not the voluntariness or otherwise of the relationship but the fact of the other's dependency, which makes her vulnerable to one's actions and choices. PPV thus tightly links vulnerabilities to correlative responsibilities: the more vulnerable one person, Mary, is to another, Sally, in terms of the degree to which Sally can affect Mary's interests, the greater is Sally's responsibility to protect Mary's interests. This explains why, for example, parents have special responsibilities to protect and promote their children's welfare because a child's present and future welfare are especially vulnerable to her parents' actions and choices.

PPV highlights the conceptual connections between vulnerability, harm, and exploitation, making it easy to identify the potential for harm and exploitation in

relationships involving asymmetries of dependency, power, ability, resources, education, or need. Exploitation, in Goodin's view, involves taking unfair advantage of other people (194). Relationships involving inequalities of vulnerability or dependency create opportunities for more powerful persons, such as Sally, to take unfair advantage of more vulnerable persons, such as Mary, particularly in situations where Sally exercises discretionary control over resources that Mary needs and cannot obtain elsewhere (195–201). PPV thus imposes an obligation on the more powerful party in such situations not only to be particularly vigilant in guarding against the misuse of their position of power, authority, or privilege to take unfair advantage of others, but also to protect those who are vulnerable to them.

We are sympathetic to Goodin's critique of overly voluntarist and contractual models of moral obligation; his stress on the moral significance of relationships of dependency and interdependency resonates with similar themes in feminist ethics and bioethics.4 Nevertheless, we have some difficulties with Goodin's consequentialist approach to vulnerability and obligation. One problem with PPV is that Goodin claims the causal history of a relationship is irrelevant in determining the responsibilities arising from vulnerability (127). So, whether Mary's vulnerability is the direct result of Sally's actions, the result of events or actions in which Sally played no part, or even due to Mary's own actions, what generates Sally's responsibility is her capacity to provide aid, not whether or not Sally played any causal role in making Mary vulnerable to her. It is thus the vulnerable agent's needs and the responsible agent's capacity to meet them that define the limit of the responsible agent's responsibility. However, as Kittay has argued, causal history is not irrelevant to the moral warrant of vulnerability-responsive obligation (1999, 59). How or why we find ourselves in a position where another is vulnerable to us is often crucial in determining not only whether or not the allocation of responsibility for that vulnerability is morally warranted or just, but also what kind of response to the other's vulnerability is morally appropriate. This issue is particularly pertinent in social policy contexts, as we discuss in the next section of the paper.

Goodin argues that PPV not only explains responsibilities arising from vulnerability in relationships involving inequality, but can also ground broad social welfare obligations. The expansive scope of the principle thus raises the previously discussed challenge that if everyone and everything is potentially vulnerable, the concept of vulnerability seems to lose its purchase in helping to determine moral priorities. Goodin's response is that "the principle of protecting the vulnerable is first and foremost an argument for aiding those in dire need"

(111). We agree that many human vulnerabilities arise from needs and that vulnerabilities of need generate moral obligations and duties of justice. Because we are complex, embodied, social, affective, and intelligent beings, we have a range of needs which must be met in order to flourish, from basic needs for nourishment and shelter through to complex social needs, for example, for friendship and meaningful work. However, given the diversity of human needs, not all needs are equally morally demanding, thus raising the question of which needs and correlative vulnerabilities ought to be given moral priority.

This is a large and complex question, which we cannot answer in any detail here. However, we are in general agreement with Goodin and with needs theorists (Reader 2005, 2006, 2007; Wiggins 1991, 2005) that "vital needs"—those that are inescapable and without which the being in question will be seriously harmed or fail to flourish—ought to be given moral priority. The notion of "vital needs" should not, however, be interpreted narrowly as applying only to universal basic needs for bodily sustenance and protection. Which needs are vital to a particular person will depend not only on universal facts about the human condition, but also context-specific factors about her social, political, and personal situation and identity (Reader 2006). Thus an interesting aspect of needs theory, which makes it particularly relevant for developing a context-sensitive analysis of vulnerability, is that it attempts to reconcile a universal claim about the normativity of needs (i.e., people ought to respond to the needs of others) with a context-sensitive analysis investigating specific needs claims that are inevitably socially, culturally, and politically contestable.⁷

The understanding of vulnerability that emerges from Goodin's view and from needs theory is as follows: to be vulnerable is to be susceptible to serious harms (physical, psychological, and emotional) with respect to the meeting of one's vital needs—harms that impair one's ability to lead a flourishing life.⁸ The fact that we all have needs explains why vulnerability is an ontological condition of our humanity. However, persons who are more than ordinarily vulnerable are those who have occurrent needs, which they may not be able to meet themselves without assistance. Vulnerability, then, is a matter of degree, depending on how many of a person's needs are occurrent, and the extent of assistance that may be necessary to meet those needs (Reader 2006, 344).

One problem with this analysis of vulnerability, however, is that the focus on obligations to meet needs and avoid harm, however important, does not pay sufficient attention to obligations to foster agency and autonomy. A significant problem with Goodin's view, for example, is that although he claims that the

notion of "interests" (and the correlative notion of harm or threat to one's interests) is open to a wide range of interpretations, so that it might, for example, encompass interests in autonomy or self-respect, his account does not recognize or address the challenge of reconciling the normative obligations arising from vulnerability with the normative obligation to respect autonomy. This problem arises, in part, because PPV aims to "protect" the vulnerable, and not to promote their agency. But by failing to address questions of agency and autonomy, Goodin's principle of "protection" potentially opens the door to the kinds of unwarranted paternalism we have seen in bioethics. For this reason, we want to take a more pluralist approach to obligation, and to balance the obligations arising from vulnerability with other obligations, such as those arising from autonomy.

John O'Neill (2005) identifies one reason why responding to the moral demands arising from vulnerability may seem inconsistent with respect for autonomy—because vulnerability is often associated with a humiliating dependency on others that seems inconsistent with a conception of the autonomous agent as self-sufficient, independent, and able to meet her own needs.9 In response to this concern, O'Neill observes that "the existence and recognition of common vulnerability . . . robs the fact of dependency of its potentially humiliating condition" (93) and that such acknowledgment requires a rejection of excessively individualistic conceptions of autonomy. We agree. We think one of the reasons why 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. It also requires us to rethink the meaning of autonomy (Agich 1990). If human persons are both vulnerable and capable of autonomy, then we need an account of autonomy that is premised on recognition of human vulnerability, and we need an analysis of vulnerability that explains why we have obligations not only to protect vulnerable persons from harm, but to do so in a way that promotes, whenever possible, their capacities for autonomy.

Although we cannot argue for this claim in any detail in this paper, relational theories of autonomy (e.g., Anderson and Honneth 2005; Mackenzie and Stoljar 2000; Meyers 1989) provide the most promising approach to reconciling autonomy with the normative obligations arising from vulnerability. Relational theorists argue that autonomy is a socially constituted capacity, which is developed, sustained, and exercised only with extensive social scaffolding and support. Further, because autonomy is a socially constituted capacity, its development can be impaired and its exercise thwarted by exploitative or

oppressive interpersonal relationships, and by repressive or unjust social and political institutions. This approach to autonomy is thus premised on the fact of our inescapable dependency on, and hence vulnerability to, others. Moreover, because relational theorists regard agency and some degree of autonomy as important for a flourishing human life, a relational approach is committed to the view that the obligations arising from vulnerability extend beyond protection from harm to the provision of the social support necessary to promote the autonomy of persons who are more than ordinarily vulnerable.¹⁰

We conclude this section by proposing a brief taxonomy of three different, but overlapping, kinds of vulnerability: *inherent*, *situational*, ¹¹ and *pathogenic*. This taxonomy allows us to more carefully distinguish among different sources and kinds of "more than ordinary vulnerability."

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. The extent of a person's inherent vulnerability will vary depending on a range of factors, such as age, gender, health status, and disability. It will also vary depending on a person's resilience and capacity to cope, and the extent of social support available to them. 12

A second source of vulnerability is situational vulnerability, by which we mean vulnerability that is context-specific, and that is caused or exacerbated by the personal, social, political, economic, or environmental situation of a person or social group. Situational vulnerability may be short term, intermittent, or enduring. For example, a family whose home has been damaged by flood waters and who are living in emergency accommodation for several weeks may be vulnerable by virtue of their situation. But if they live in an affluent country, are insured, relatively financially secure, and supported by government assistance, this situational vulnerability will only be temporary. By contrast, if they live in a poor country, with no or limited support from government or non-government agencies, the effect of being displaced from their home may be catastrophic and enduring, rendering them more or less permanently vulnerable.

Both inherent and situational vulnerability may be dispositional or occurrent. All human beings are dispositionally vulnerable to hunger. But most of those of us who live in affluent countries are not occurrently vulnerable to lifethreatening hunger on a daily basis, unlike a significant proportion of the world's population who lack the resources to supply their daily nutritional needs. Similarly, all fertile women of childbearing age are potentially vulnerable to life-threatening complications in childbirth. But women's mortality rates from

such complications vary enormously, depending on a range of individual, social, and cultural factors, such as their relationship status, medical history, socio-economic status, geographical location, and cultural norms relating to pregnancy and childbirth.

Inherent and situational vulnerability give rise to specific moral and political obligations: to support those who are occurrently vulnerable; and to reduce the risks of certain individuals, groups, and populations to avoidable occurrent vulnerability, for example, through targeted interventions aimed at remediating specific vulnerabilities. In keeping with our commitment to autonomy and fostering capabilities, we would argue that the background aim of any such interventions must be to enable or restore the agency of vulnerable persons or groups, and that this is most likely to be achieved by interventions that engage their agency and participation, wherever possible and to the greatest extent possible.

In contrast to agency-supporting responses to vulnerability, some responses may exacerbate existing vulnerabilities or generate new vulnerabilities. We refer to these as *pathogenic* vulnerabilities. There are a variety of sources of pathogenic vulnerability. Pathogenic vulnerability may be generated by 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. For example, people with cognitive disabilities, who are occurrently vulnerable due to their care needs, are susceptible to pathogenic forms of vulnerability, such as sexual abuse by their carers. Other forms of pathogenic vulnerability arise when social policy interventions aimed to ameliorate inherent or situational vulnerability have the paradoxical effect of increasing vulnerability (as discussed in Section 3).¹³

A common thread linking all these kinds of vulnerabilities is that they can engender a troubling sense of powerlessness, loss of control, or loss of agency. Our emphasis upon obligations to foster or restore agency wherever possible is motivated by recognition of this aspect of vulnerability. However, we acknowledge that in some situations, such as incapacitating illness, this sense of powerlessness cannot necessarily be remediated (Hoffmaster 2006). A key feature of pathogenic vulnerability is the way that it undermines agency or exacerbates a sense of powerlessness.

In the final section of the paper, we discuss an example of a social policy intervention ostensibly aimed at protecting vulnerable communities that in our view has given rise to pathogenic forms of vulnerability, and contrast this with another social policy intervention that promises to better address existing

vulnerabilities. Through these examples, we consider the implications for bioethics of developing a conception of vulnerability that is not narrowly focused on protection against harm, exploitation, or capacity for autonomous choice.

Section 3: Implications of a vulnerability approach

To illustrate the policy implications of a nuanced and well-theorized vulnerability approach, we critically assess two recent Australian public policy developments relating to health and social justice that have arisen ostensibly in response to vulnerability. The first, the federal government's Northern Territory Emergency Response (NTER) manifests pathogenic vulnerability and equates vulnerability with both vulnerability to harm and limited competence. This example is relevant to bioethics as it demonstrates the complex relationships between policies intended to protect and promote children's health, social disadvantage, and pathogenic vulnerability. The second example, the proposal by the Productivity Commission to develop universal disability insurance, promises a more appropriate set of responses to the vulnerability caused by disability, regardless of how caused. These examples seek to demonstrate how, within social policy contexts, the identification of a person or group as "vulnerable" can lead to unjustified paternalism ("labeling"); and the ways in which policies intended to support the vulnerable can lead to what we have described as "pathogenic vulnerability." These examples also highlight the need for a more nuanced theory of vulnerability that can attend to social and relational factors shaping vulnerability.

The Northern Territory Emergency Response

In Australia in 2007, the Northern Territory Government released an important report in response to allegations of a disproportionately high incidence of sexual abuse of children in remote Aboriginal communities and the impact of childhood sexual abuse on the lifetime health and wellbeing of those children. The Report of the Northern Territory Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse (Wild and Anderson 2007) was commissioned "to find better ways to protect Aboriginal children from sexual abuse" (40). The report offered an analysis of the causes of the sexual abuse of children that attended to the range of sources of vulnerability relevant to understanding the issue. It noted the inherent sources of vulnerability that make children vulnerable to sexual abuse, for example, the physical vulnerability of children, the needs of children for support and protection, and the impact of sexual abuse on

physical and mental health. It also recognized situational sources of vulnerability affecting Aboriginal children in the Northern Territory, including the remoteness of many Aboriginal communities from counseling, health, child protection, and police services; and the disproportionate social disadvantage experienced by members of these communities (62).

Importantly, the *Inquiry* was also sensitive to the possibility of pathogenic sources of vulnerability that are relevant to the situation in many Aboriginal communities, which have experienced a history of dispossession, racism, and paternalistic intervention and placement of children under care of the Protector of Aborigines mandated by the *Northern Territory Aboriginals Act 1910* (see Australian Human Rights Commission 1997):

[M]any of the Aboriginal people the Inquiry spoke with, saw the history of colonisation, non-Aboriginal people and the non-Aboriginal 'system' as responsible for the present child sex abuse problems. (Wild and Anderson 2007, 60)

The *Inquiry* recognized the complexity of factors shaping the vulnerability of Aboriginal children to sexual abuse, and made recommendations that responded to this complexity by attending to needs, protection against harm, development of social capability, and the importance of local agency. The public policy response to this report, however, did not incorporate this rich and nuanced understanding. The policy response emphasized vulnerability to harm, stigmatized Aboriginal communities, and failed to attend to the need for local control and engagement with the policy response, thereby creating the conditions for pathogenic vulnerability, despite the clear aims of the policy to protect vulnerable children.

Under the leadership of then Prime Minister John Howard, the Commonwealth government treated the situation relating to child sexual abuse in the Northern Territory as an emergency that justified extraordinary legislative intervention, enacting or amending five separate pieces of legislation. ¹⁴ At the same time, it suspended parts of the *Racial Discrimination Act* (1975) and the Northern Territory Anti-Discrimination legislation that related to the Northern Territory Emergency Response (NTER).

These responses emphasized the protection of the physical health of children, through health checks, ¹⁵ measures to reduce violence and access to alcohol and pornography, and an increased police presence in remote communities. In addition, the NTER sought to direct the use of family incomes, through "income management" measures that restricted the use of Commonwealth income support received by Aboriginal and Torres Strait Islander (ATSI) families in the Northern Territory

to licensed community stores. Finally, the NTER sought to improve school attendance and access to appropriate housing for families in the Territory.

Aboriginal and Torres Strait Islander community responses to the NTER are mixed, with some of the provisions of the NTER being welcomed in a number of communities. Nonetheless, in both the Report of the NTER Review Board (2009) and the report on the health impacts of the NTER conducted by the Australian Indigenous Doctors' Association (AIDA 2010), the fundamental structure of the NTER is criticized for focusing too narrowly on government intervention in the absence of engagement with indigenous communities to secure cooperation and recognition of the broader historical background shaping those communities and the potentially harmful cultural impact of aspects of the NTER. The AIDA report commented that there was little correlation between the Wild and Anderson report and the NTER in the scope and approach used (13). The NTER appears to locate the problem of child sexual abuse as a failure of those indigenous communities and families, rather than recognizing the effects of colonization and systemic disadvantage on those communities. Communities were excluded from the decision making intended to benefit them: "the Intervention has diminished its own chances of succeeding in improving the health and wellbeing of children and communities through its failure to engage constructively, respectfully, and fully with the Aboriginal people it was intended to help" (AIDA 2010, 18). Similarly, the suspension of the Racial Discrimination Act served, in effect, to label Aboriginal and Torres Strait Islanders as incompetent citizens and was found by the NTER Review Board to have the potential to undermine the aims of the intervention:

There is intense hurt and anger at being isolated on the basis of race and subjected to collective measures that would never be applied to other Australians. The Intervention was received with a sense of betrayal and disbelief. Resistance to its imposition undercut the potential effectiveness of its substantive measures. (NTER 2008, 8)

A well-articulated vulnerabilities approach could better assist in identifying the complex relationships among culture, historical injustice, social disadvantage, and child sexual abuse that are relevant here. Such an approach would carefully articulate the different kinds of vulnerability involved: the inherent vulnerability of children, the situational features leading to occurrent vulnerability, the presence of pathogenic vulnerability, and the needs and harms involved. In addition, attention to pathogenic vulnerabilities would provide the basis for a further level of evaluation of the NTER in terms of its exacerbation or mitigation

of pathogenic vulnerability. In many cases, while the NTER has increased the level of resources available in indigenous communities, it has also made members of these communities substantially more vulnerable to legal sanction and to institutional intrusion in domestic arrangements than their non-indigenous compatriots. That is to say that the situational vulnerability of Aboriginal people has been exacerbated by the policy, due to the specific sanctions imposed by the NTER on people in Aboriginal communities. In many cases there is little evidence that these vulnerabilities generated by the NTER are justified in terms of their impact in mitigating child sexual abuse in these communities, addressing the underlying vulnerability of indigenous children, or helping to foster the development of capabilities that would lessen their vulnerability.

Productivity Commission—disability care and support

A second policy area demonstrating the potential implications of the vulnerabilities approach concerns recent Australian proposals to reduce the disadvantages suffered by all people who have or acquire disabilities (and who are not eligible for support through the Aged Pension). Recently, the Australian Productivity Commission issued a report into disability care and support (2011). The premises of the report include an acceptance that the existing system of state responsibility for provision of disability services is "underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports" (Productivity Commission 2011, 2). Its two most substantial recommendations involve the creation of two universal insurance schemes: the National Disability Insurance Scheme (NDIS) and the National Injury Insurance Scheme (NIIS).

The NIIS supplies no-fault injury insurance, providing fully funded care and support for those who suffer a workplace accident or "catastrophic injury." The NDIS aims at ensuring all Australians have support in the event of a disability independent of the cause of the disability or the state where they live, but rather based on the impact of the disability on the person and those who provide her care. The NDIS operates at three levels: Tier 1 is aimed at minimizing the impacts of disability and increasing the social participation of all people with disabilities; Tier 2 involves providing information, referral, and Web services for people with disabilities; Tier 3 involves the provision of daily support or early intervention for three groups of people whose significant and enduring disabilities merit specific support of distinct kinds (Productivity Commission 2011, 14).

The disability and injury insurance schemes together are intended to address significant inequities in the current disability support system, including inequities based on differences in disability service provision between states and inequities based on how a person comes to have a disability (e.g., whether fault must be determined to access compensation). They are also aimed at promoting resilience and reducing the impact of disability, no matter how caused, through changing social practices and attitudes of people without disabilities that limit the social participation of those who live with disabilities. In this regard, the recommendations capture the importance of attending to the different sources of vulnerability and developing targeted responses that take into account the impact of the specific social context on the experience of living with disabilities. In addition, the report seeks to avoid the labeling of people with disabilities as needing special protections, as it seeks to challenge the stigmatizing effects of disability and to enhance the scope for choice and agency by people living with disabilities. In many regards, then, the recommendations of the Productivity Commission report are consistent with the vulnerability analysis we propose and would, if implemented, protect against harms arising from vulnerability and promote resilience, autonomy, and agency.

Nonetheless, the report is insufficiently attentive to the significance of the relational character of human agency. Our analysis of vulnerability acknowledges that as embodied and developmental beings, humans are inevitably dependent on others for our care and nurture at one or more points in our lives. Eva Kittay (1999) has written about the ways in which the dependence of one person on the care of another creates a second dependency, the dependency of the person who provides care on others to attend to her needs. The Productivity Commission's report describes informal and unpaid family carers as "natural supports" for people (at least young children) with disabilities and notes that unpaid carers suffer ill health, depression, bear significant financial burdens, and have lower participation rates in paid employment than others in the community. However, the report stops short of recommending direct financial support for informal carers and family members who bear a significant portion of the social and material costs of caring for those whose disabilities make them dependent on their carers. The report notes that unpaid care accounts for the overwhelming majority of hours of care provided, but immediately states baldly: "[n]o scheme is likely to fund the full costs of this care, so natural supports will remain an important part of the care and support response" (Productivity Commission 2011, 312). The recommendation relating to the assessment of supports

required for individuals with disabilities that limit core activities states that the assessment should "consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')" and "translate the reasonable needs determined by the assessment process into a person's individualized support package funded by the NDIS, after taking account of natural supports" (Productivity Commission 2011, 70).

On our analysis, the discounting of an individual's needs on the basis of an assumption that her or his "natural supports" will provide a reasonable level of dependency care can have two effects.¹⁷ First, it exposes the disabled person to vulnerability to need or exploitation where the family carer is unwilling or unable to provide the required care or support. Secondly, it exposes the carer to a range of social and material vulnerabilities, because she is expected to take on, without assistance, the burden of providing or securing that care (Kittay, Jennings, and Wasunna 2005; Walker 1998, 86-90). Having identified the impact of caring for a disabled person on the carer's life, well-being and financial health, it is surprising that the report does not provide clearer parameters for assessing what it is reasonable for a family carer to provide, given the very real emotional, social and intrafamilial pressures on carers to bear the impact of care, and the vulnerabilities thereby created. In our view, this is an example of pathogenic vulnerability, because it reinforces, rather than identifying and addressing, the vulnerability of carers, and arises from the assumption that such responsibilities are wholly "natural" rather than the effect of social and political structures.

By identifying ways in which policies intended to mitigate vulnerabilities can unintentionally generate pathogenic vulnerability, our aim in this section has been to demonstrate the importance of a nuanced approach to vulnerability, one that is sensitive to the need to balance concerns to provide protection with concerns to foster agency and resilience. We have also shown the relevance of such an approach for critically evaluating public policy related to health and social justice that aims explicitly to respond to an area of human vulnerability.

Conclusion

We have argued that, rather than vulnerability being a property of only those people who fall into the category "vulnerable groups" or "vulnerable populations," all human life is characterized by vulnerability, and that specific factors exacerbate the vulnerability of specific individuals and groups. A focus on

vulnerability highlights our common humanity and offers grounds for solidarity. As biological and social beings, we share much vulnerability—to ill health, to bad luck, to natural and human-generated disasters, and so forth. Although these and other vulnerabilities are not equally distributed, none of us is invulnerable; we all have some experience and understanding of what it is to feel vulnerable. Appealing to our shared vulnerability is one way of grounding solidarity as a value in bioethics that may avoid a divisive "us versus them" mentality and go beyond self-interest or prudential concerns.

Just as we share much vulnerability, it is also the case that our social practices and institutions can ameliorate vulnerabilities and can help foster resilience. Rather than simply drawing attention to our shared vulnerability to harm, a fuller account of vulnerability can attend to the social practices (such as education, health promotion, access to the range of social services and legal protections) that can promote our well-being and capacities for agency, while reducing vulnerability to need, ill health, or exploitation. Linking vulnerability to vital needs and to flourishing provides an additional and cogent moral reason for action on health inequalities. Those who experience vulnerabilities of vital need are susceptible to harms that warrant responses from those with the capacity to respond: these include institutional responses aimed at supporting the agency of those who are vulnerable, as well as ensuring access to appropriate support and care. A carefully developed account of vulnerability will assist in understanding the ways in which institutions and practices, including those related to health, shape people's inherent and situational resilience and vulnerabilities; and in developing respectful responses to these vulnerabilities.

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Notes

- 1. We understand harm broadly, to encompass both physical and emotional harms. As we discuss later, vulnerability is also often associated with a sense of loss of agency or powerlessness (Hoffmaster 2006).
- 2. Like Kipnis, Rogers and Ballantyne (2008) aim to identify various sources of vulnerability in research participants, classifying these as intrinsic and extrinsic. Like Hurst (2008), they also aim to guide research ethics committees. They recommend interventions to address specific vulnerabilities that may give rise to inadequate consent or likelihood of exploitation.

- 3. This question as formulated does not distinguish between the view that vulnerability itself gives rise to obligations (Goodin 1985), and the view that vulnerability flags obligations that arise from other moral claims (Hurst 2008). While a fully articulated theory of vulnerability would need to take a stand on this issue, this task is beyond the scope of this paper.
- 4. See, for example, Kittay (1999) and Walker (1998), both of whom are influenced by, and critically engage with, Goodin's theory of vulnerability.
- 5. Goodin also thinks that PPV can ground obligations to future generations, animals, and the environment. It is beyond the scope of our concerns in this paper to address this issue.
- 6. Wood, in his analysis of the relationship between vulnerability and exploitation concurs that "many human needs and desires can be viewed as vulnerabilities" (1995, 143).
- 7. An issue that requires further discussion than we can provide here is whether there is a tension between the concept of "vital needs" and the inherent social and political contestability of needs claims. On this issue, see Fraser's (1989) discussion of the "politics of need interpretation." We agree with Fraser about the importance of dialogical processes of need interpretation that engage the active participation of those affected. As we discuss in the next section, such participatory processes are essential for respectful social policy responses to vulnerability.
- 8. Here we take "flourishing life" to refer to the best possible life for a person given his or her capacities.
- 9. Both Agich (1990) and Hoffmaster (2006) have discussed this point in relation to aging and long-term care.
- 10. See Anderson and Honneth (2005) for a related argument from a recognition theoretic perspective. Their argument questions the adequacy of liberal theories to address the justice claims arising from autonomy-related vulnerabilities. Given capability theory's concern with fostering agency, we would argue that the justice obligations arising from vulnerability might be better articulated by a capabilities approach to justice (see e.g., Nussbaum 2000, 2011; Sen 1992, 2009) than by either liberal theories or consequentialist theories, such as Goodin's. It is beyond the scope of our concerns in this paper to defend this claim here. It should be noted, however, that we disagree with Fineman, who claims, we think incorrectly, that a capabilities approach "perpetuates social inequality in dangerous ways" (Fineman 2008, 14, n. 39).
- 11. Dunn, Clare, and Holland (2008) also make a distinction between inherent and situational vulnerability.
- 12. The literature on vulnerability in nursing has emphasized the importance of both objective ("etic") and subjective ("emic") dimensions of vulnerability (see, e.g., Sellman 2005; Spiers 2000). "Etic" approaches focus on a range of objective risk factors that might make an individual or group more than ordinarily vulnerable; "emic" approaches focus on the subjective experience of vulnerability, noting that factors such as individual coping skills and the extent of social support may have a significant positive or negative impact on subjective experiences of vulnerability.
- 13. Our notion of "pathogenic vulnerability" overlaps, to some degree, with Turner's notion of "institutional precariousness" in relation to human rights protections. Turner

argues that human rights legislation evolves in response to the "dynamic and dialectical relationship between institutional precariousness and ontological vulnerability" (2006, 32): on the one hand, human rights protections are a response to human vulnerability and strong and well-functioning states are necessary for providing such protections; on the other hand, institutional structures are often fragile and precarious and state power is often the cause of human rights abuses. We agree with Turner that institutions are one source of pathogenic vulnerability, but our notion is more extensive; we think interpersonal relationships as well as institutional structures can be sources of pathogenic vulnerability.

- 14. Northern Territory Emergency Response Act (2007), the Social Security and Other Legislation Amendment (Welfare Payment Reform) Act (2007), and the Families, Community Services and Indigenous Affairs and Other Legislation Amendment (Northern Territory National Emergency Response and Other Measures) Act (2007).
- 15. Initially announced as mandatory health checks, the NTER changed the status of these checks to voluntary health checks following objections to mandatory checks by health service providers.
- 16. The Productivity Commission has released three related policy proposals and these distinguish in their focus between disability, injury, and aged care, while also recognizing that each of the three requires appropriately targeted publicly funded support. The Disability Care and Support Report separates disability acquired through a workplace accident or catastrophic injury (supported in part by the National Injury Insurance Scheme [NIIS]) from those disabilities covered by the National Disability Insurance Scheme [NDIS]), and distinguishes disability from aged care (care aimed at people over the age for receipt of the aged pension, currently those over 65, but rising to those over 67 in the next 20 years). The report noted that this distinction must reflect the needs of individuals who may require care into old age based on a pre-existing disability and desire continuity of service provision into old age (Productivity Commission 2011, 16-17). The report includes within its definition of severe disability "severe core activity limitations" (which may be occurrent) and "profound [permanent] core activity limitations" due to "diseases of the nervous system, intellectual and developmental disorders, mental illness, diseases of the circulatory, respiratory, and digestive systems, cancers, and diseases of the musculoskeletal system" (96).

17. The Productivity Commission report assesses the support needs of individuals in relation to "what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')" (Productivity Commission 2011, 69). This reinforces the vulnerability of some carers who might previously have had access to financial support through the Carer's Pension or who might be unable to provide the level of care and support that it is thought is reasonable for those carers to provide. Both the carer and the person who has a disability are made more vulnerable through this aspect of the policy because the support package to assist in the care of the person who is disabled could be reduced, exposing both to increased exposure to material (and social) need.

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