

Biotechnology, Justice and Health

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ABSTRACT

New biotechnologies have the potential to both dramatically improve human well-being and dramatically widen inequalities in well-being. This paper addresses a question that lies squarely on the fault line of these two claims: When as a matter of justice are societies obligated to include a new biotechnology in a national healthcare system? This question is approached from the standpoint of a twin aim theory of justice, in which social structures, including nation-states, have double-barreled theoretical objectives with regard to human well-being. The first aim is to achieve a sufficient level of well-being in each of six core dimensions. In the special case of healthcare systems, this aim is focally but not exclusively attentive to achieving health sufficiency as one of the core dimensions. The second aim is to combat the emergence and persistence of densely woven patterns of systematic disadvantage that tend to undermine the achievement of a sufficient level of health and the other core elements of well-being of some persons and groups. Judgments about entitlements to health related resources, including new biotechnologies, are made in light of a threshold notion of health sufficiency. What is enough or sufficient health? The answer that is defended here is that sufficient health is enough health for a decent human life, understood as enough health to live a full life course without preventable, significant functional disability or decrement in health, or treatable pain or suffering. When a state must include a new biotechnology in its national healthcare system is also influ-

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enced by ancillary concerns about the connection between health and other core dimensions of well-being. What counts as a significant functional impairment or health decrement is thus explicated, in part, in relation to the theory's sufficiency aim for the other essential dimensions of well-being, and thus for a decent life, overall. Those elements of health that play a critical role in the experience of sufficient reasoning, affiliation, security, respect and self determination are especially important; any loss of health function or capacity that threatens the individual's prospects for sufficiency in these other dimensions, including the relational egalitarian concerns they entail, constitutes a significant functional impairment. Within national borders, individuals are thus entitled to those health-related goods and services that are essential for a sufficiency of each of the dimensions of well-being; with regard to self determination and respect, what is sufficient by way of guaranteed access to specific goods and services is going to depend on the implications of such access for where an individual stands in relation to her co-nationals. The content of any entitlement to health-related goods and services is also necessarily dynamic. What can be done for health and the other core dimensions of well-being as a function of technological innovation and diffusion is in constant flux. The paper concludes by considering the implications of this analysis for the conditions under which states are obligated to include access in their healthcare systems to one biotechnology, deep brain stimulation.



New biotechnologies have the potential both to dramatically improve human well-being and to dramatically widen inequalities in well-being. In this paper, we tackle a question that lies squarely on the fault line of these two claims: When, as a matter of justice, are societies obligated to include a new biotechnology in a national health care system or otherwise ensure that all have reasonable access to it?

The paper proceeds in three parts. We begin by explicating one way of thinking about this question by providing a very brief sketch of our twin aim theory of justice as presented in our book, *Social Justice* (Powers and Faden 2006), and a new book currently in progress. In Part Two, we focus on the concepts of a decent life and sufficiency, which play prominent roles in our theory by helping to explicate what goods and services individuals are entitled to receive. In Part Three, we illustrate some of the implications of our approach by looking more carefully at an existing neurotechnology, deep brain stimulation, that has some promising new applications.

PART ONE: A TWIN AIM THEORY OF JUSTICE

For us, claims about justice in access to healthcare goods and services draw their foundational legitimacy—their ultimate justificatory structure—from the essential and direct role that these goods play in human well-being, which we take to be the primary object of social justice. Ours is a twin aim theory of justice, in which social structures, including both global institutions and nation-states, have double barreled objectives or aims with regard to human well-being. The target of each barrel is morally distinct from the other, but strategically reinforcing.

One aim is the improvement of well-being. In the special case of healthcare systems, this aim is focally but not exclusively attentive to improving health as a core dimension of well-being. The other aim is to combat, whether by prevention or amelioration, the adverse effects on well-being caused by densely woven patterns of systematic disadvantage that profoundly compromise (or will compromise) the health and other core elements of well-being of some persons and groups.

The well-being aim begins with a broadly Aristotelian-inspired effort to identify some core components of human well-being that are suitable objects of concern within a theory of justice. We specify core elements of human well-being as having three characteristics. They are (1) typical of normal human development and valuable for their own sakes, apart from any further good they might bring; (2) of value to anyone, on reflection, whatever their particular life projects, chosen activities, or personal aspirations might be; and (3) humanly alterable and profoundly and pervasively influenced in their development and maintenance by basic social institutions and social practices.

THE WELL-BEING AIM AND ITS CORE ELEMENTS

The well-being aim of social justice is defined in terms of a level of sufficiency of each of its core elements. Although it is beyond our task here to give full consideration to how sufficiency for any element is assessed, we will have more to say about this later, particularly with regard to health. The key point for now is that sufficiency represents a moral minimum of justice. Inequalities in well-being in which individuals fail to meet even this moral minimum are among those most morally urgent to address.

Our list includes six core elements. Though these six overlap in terms of both determinants and effects, each is of independent and equal moral value.

1. We have already mentioned health. Although health is the element of human development and flourishing most intimately connected with the biological or organic functioning of the body, the absence of health refers to more than biological malfunctioning or impairments. Being in pain—even if that pain does not impede proper biological functioning—sexual dysfunction, and infertility are also incompatible with health.

2. The second element is personal security from actual physical and psychological harm, as well as the threat of such harm.

3. The third element is the development of reasoning, both for deliberation and choice and for the formation of beliefs and inferences regarding facts about the natural and social world.

4. The fourth element involves the formation and maintenance of personal attachments of various kinds with varying degrees of intimacy, commitment, and affective engagement.

5. The fifth element is the respect of others. Here, the central concern is that individuals should be able to live under social conditions in which others judge and treat them as moral equals, as persons worthy of the same sort of treatment any other person merits; and among co-nationals, as fellow citizens, as persons having comparable political standing.

6. The sixth element is self-determination, the ability to shape the broad contours of a life, to have some significant say over the general course of one's life. Put slightly differently, self-determination is about living a life that is not in crucial respects under the domination and control of others or the tyranny of profound necessity.

The importance of these last two elements to our overall account of well-being cannot be overstated. Whether in the domestic case, in which equal moral standing

and political standing are at issue, or in the international case, where moral equality is the paramount concern, the intention is that no-one should face the tyranny of deprivation or the threat of domination or oppression of others. Thus, ensuring sufficient well-being involves securing two important goods: the good of living a self-determining life and the good of having a social standing involving the respect of others.

THE SYSTEMATIC DISADVANTAGE AIM

The core concern of this aim of justice centers on systematic disadvantage. Systematic disadvantage occurs in a variety of familiar forms. Ethnic and gender-based oppression are paradigm examples, as are pervasive forms of economic and cultural subordination. In each of these, the causal vectors of disadvantage are multiple and mutually reinforcing. In the worst instances, systematic disadvantage exhibits a cascading effect in which each deficiency in one dimension of well-being contributes causally to the reduction of well-being in some other respect (poor health leads to impairments in reasoning, for example). Multiple strands of the densely woven vectors of disadvantage thereby magnify and increase the risk of negative consequences across the board. The result is that the greatly diminished well-being prospects for those who are systematically disadvantaged are compounded, perpetuated, and sustained over the course of a lifetime and, frequently, over the course of generations.

It is important to emphasise that the impact of patterns of systematic disadvantage is not equal across the course of life, and is not solely a result of greatly restricted opportunities for choice among mature, autonomous adults. When experienced in childhood, as is frequently the case with extreme poverty, the negative effects of systematic disadvantage at this critical stage in human development can be so devastating as to put the prospects for a decent adult life permanently out of reach.

In short, our theory is meant to include a special concern for the familiar forms of systematic disadvantage inherent in various forms of subordination or oppression based on group membership and resulting from extreme poverty; but our critique of systematic disadvantage also encompasses any kind of social structural impediments to securing sufficient well-being—and thus to human development—in the earliest stages of life, even when its predictable consequences are not intended.

PART TWO: SUFFICIENCY AND A DECENT HUMAN LIFE

To summarize, then, our twin aim theory of justice has as its focal object the design of social arrangements having profound and pervasive impact on well-being. The first aim is to achieve a sufficient level of well-being in each of the six core dimensions. The second aim is to combat the emergence and persistence of densely woven patterns of systematic disadvantage that tend to undermine the achievement of a sufficient level of well-being in each of its core dimensions.

As we have already noted, each dimension is essential in that a reflective agent, taking stock of the most basic requirements for a decent human life, would want each one, whatever else she might want; and she would judge that none is reducible to others on the list. While a decent human life is surely possible for persons lacking in some core dimension—those who are in poor health, for example—each dimension earns a place on the list because of its presumed contribution to a good life for anyone, whatever their particular life plans and projects. Moreover, each is relevant to creating just social arrangements, since these arrangements exert profound and pervasive influence over the course of a life and should therefore reflect factors that are important to ensuring well-being.

There is much that could be said about the work that the notion of a decent human life does within our theory. A few comments should suffice for now. A decent life requires more than mere subsistence, for example, but less than a maximally flourishing life for all. These points are familiar from contemporary discussions of human rights, which aim to articulate the minimum demands of a transnational standard of well-being (Nickel 2007: 61–66, 98–103, 138–42; Buchanan 2010).

In addition, in accordance with relational egalitarian concerns, our account of a decent life involves the goods of respect and self-determination. In this respect, our account is comparable with a position taken in the human rights literature. James Nickel, for example, suggests that human rights may involve reasonable claims for things other than food, shelter, and education; such as some measure of control over one's own life and some social guarantees of equal standing in political and legal arenas (Nickel 2007: 63–64).

Having emphasised self-determination and respect in our account of well-being, we can make a few observations about what would be *contrary* to a decent life. A decent life is not one that is marked by servility, slavishness, the necessity to grovel, or deep dependence on the good will or whim of others for the most basic requirements of

life. A decent life is not one marred by the most degrading aspects of poverty, including squalor, helplessness, extreme vulnerability, or the inability to provide for one's own children and family (Powers and Faden 2006: 138–41, Margalit 1998). A decent life cannot involve being treated as less than a full member of the human community or having one's most vital concerns accorded little or no weight. Indeed, to be treated as a second-class citizen within one's own society is to be treated as a second-class human being, as someone who is not due the full measure of respect and concern accorded to other members of a common political community (Margalit 1998).

A decent human life does not involve being subjugated, marginalised, stigmatised, infantilised, or deprived of the full use of one's mature faculties.²² Much more might be said along these lines, but the essential point we make here is that these relational aspects of well-being earn a place on the list of constituents of a decent human life as securely as concerns about health, cognitive development, and physical security. Moreover, they function as a check on how we should understand what counts as sufficiency for other constituents such as health.

Both the notion of a decent human life, and the relational egalitarian concerns that are built into our conception of well-being, bear on what counts as sufficiency in health. They also bear on our answers to questions of entitlements to health care goods and services instrumental to health sufficiency. We identify minimal conditions for health, for example, in part by reference to the impact of relative inequalities on social standing and the ability of individuals and groups to lead self-determining lives and avoid the kinds of conditions inimical to a decent human life. We then make judgments of entitlements to health related resources, *including new biotechnologies*, in light of that notion of health sufficiency, influenced by ancillary concerns about the connection between health and other core dimensions of well-being and how resource policy choices impact the full set of well-being concerns.

HEALTH SUFFICIENCY AND HEALTHCARE ENTITLEMENTS

What is enough for sufficient health? And what instrumental goods and services, what resources, are individuals entitled to as a consequence?

Our answer to the first question is: people must have enough health for a decent human life. For us, this means enough health to live a full life course without signifi-

2. Many of these points are developed in Mill 1869, which has influenced our own views about what is central to well-being in the context of a decent human life.

cant disability or decrement in health, or pain or suffering that can be reasonably prevented, treated or relieved. Clearly and intentionally, this is a higher threshold than one that would require only enough health to escape severe pain or suffering, death in childhood or early adulthood, or the most egregious of disabilities.

At the same time, however, our requirements fall short of what is demanded for a maximally flourishing life, which would involve maximal health for all. That the world's oldest person just celebrated his 115th birthday in Japan, and increasing numbers of people in many countries are now living into their 90s, do not entail that the threshold of health sufficiency requires all to do so. It is sufficient that all live through each stage of life, including old age. Similarly, health sufficiency does not require the absence of any and all limitations on health-related quality life. It is enough that all live lives unmarked by significant disabilities or decrements in health that could reasonably be prevented or mitigated, and pain and suffering that could be alleviated.

What counts for us as a significant health decrement is explicated, in part, in relation to our theory's sufficiency aim for the other core dimensions of well-being, and thus for a decent life overall. Those elements of health that play a critical role in the experience of sufficient reasoning, affiliation, security, respect and self determination are especially important; any loss of health function or capacity that threatens the individual's prospects for sufficiency in any of the other dimensions, including the relational egalitarian concerns they entail, constitutes a significant impairment.

What instrumental goods and services, what resources, are individuals entitled to as a consequence of this sufficiency threshold?

Our formal answer is deceptively simple. Individuals are entitled to those health-related goods and services that are required for a sufficiency of health and the other essential dimensions of well-being, as needed for a decent life. With regard to self determination and respect, what is sufficient by way of guaranteed access to specific goods and services depends on an individual's relation to her co-nationals, who also require access.

The global and domestic health-related goods and services to which an individual is entitled will change over time. What can be done to protect, restore and promote health and the other essential dimensions of well-being is constantly changing as a result of technological innovation and diffusion, as well as cost and value.

At minimum, interventions that produce at least moderate value at no more than moderate cost are likely candidates for inclusion in the content of the entitle-

ment. For us, the value of a health intervention is defined not only in terms of its impact on health morbidity or life expectancy or pain, but also in terms of the effect it might have on prospects for achieving sufficiency with regard to reasoning, affiliation, security, respect and self determination. Thus, for example, the value of providing contraception includes not only its impact on a woman's prospects for surviving into older age, but also how control over whether and when to become a parent affects her prospects for living a life that is sufficiently self determining, with adequate social respect and sufficient capacity to care for those she loves. Also, in some cases, value can permissibly be cashed out not only in terms of the impact on the well-being of those who are the direct recipients of a health good or service, but also on the well-being of those who care for them, such as the loved ones of people with special needs.

The national entitlement may also include interventions that are higher cost or lower value, but only when this would not negatively impact the availability of essential goods and services required by all citizens. Here, our theory mirrors, with a moral grounding rather than a strict efficiency grounding, the concern captured in allocational efficiency in economics to avoid expenditures and entitlements that 'crowd out' goods and services that are necessary to secure sufficient well-being or a decent human life.

Also, it is important to emphasise that sufficiency in health and the other dimensions is pegged to a decent life, and not an infinitely elastic notion of human flourishing. To do otherwise would result in another kind of unacceptable crowding out, in which valuable goods such as the arts, play and recreation are pursued at the expense of goods more basic to well-being.

PART THREE: NEW BIOTECHNOLOGIES AND THE EXAMPLE OF DEEP BRAIN STIMULATION

We turn now to the question of with which this paper began: When, as a matter of justice, are societies obligated to include a new biotechnology in a national health care system or otherwise assure that all have reasonable access to it?

Consider the example of deep brain stimulation (DBS). In DBS, guide wires are inserted through the skull and into the brain, where they deliver electrical currents to clusters of neurons that are no longer performing properly. DBS was first

employed to control the tremors of Parkinson's disease and is now routinely used in many countries to treat other movement disorders, such as seizures and Tourette's, along with recalcitrant depression.

In early 2012, the *New England Journal of Medicine* reported the results of an experiment to use DBS for yet a different purpose: to boost failing memory (Suthana et al. 2012). Two key memory regions of the brain were stimulated in 7 seizure patients, all of whom showed improved cognitive performance during stimulation. These findings have generated excitement about the prospect that DBS might become an effective treatment for dreaded memory disorders like Alzheimer's. Diseases and injuries that interfere with cognitive processes threaten prospects for sufficiency in virtually every dimension of human well-being. As patients with progressive dementias lose the capacity to recall even the basic who, what, where and when of their everyday lives, their suffering, and that of the people who love them, is enormous.

Much more work needs to be done to establish whether DBS will prove effective in preventing or mitigating the ravages of Alzheimer's and other severe memory-impairing disorders. However, assuming it does, and assuming that providing DBS to all relevant patients does not impact too negatively on responding to other sufficiency claims, then patients with Alzheimer's and the like would certainly be entitled to DBS under our sufficiency standard.

But also consider the following. Some of the seven epilepsy patients in the aforementioned experiment were *not* suffering from memory impairments that sometimes accompany seizure disorders, yet *all* of them did better on the cognitive tasks when their brains were being stimulated. This suggests that some people with normal cognitive function will likely seek DBS (or some other non-invasive neurotechnology such as transcranial magnetic stimulation) solely to get an intellectual edge.

We are now in the familiar and contested territory of the ethics of human enhancement, a complex set of issues that has generated a substantial literature (Buchanan 2011; Savulescu and Bostrom 2009, Harris 2007, President's Council on Bioethics 2003). We engage here only with one of these issues: the contentious relation between enhancement and justice, to which our account of sufficiency has at least a partial response.

Some argue that what is most morally troubling about biotechnological enhancements is their potential to exacerbate or create egregious inequalities in human

well-being. Some even hold that these technologies and social justice are on an inevitable collision course. Here we agree with Allen Buchanan's trenchant analysis that these criticisms are both overgeneralised and misguided (Buchanan 2011).

Even if it were possible to draw a sharp line between new biotechnologies that protect or restore health and new biotechnologies that enhance health or other dimensions of well-being, that difference would not entail that therapies and enhancements pose fundamentally different challenges for the kind of justice theory that we defend. In both cases, the same basic question is raised: as the technology diffuses, under what conditions, if any, are individuals entitled to it as a matter of justice?

Whether a biotechnology that enhances memory or any attribute critical to reasoning and cognitive performance should become a service to which individuals are entitled depends at least in part on the impact of access to that technology on considerations of relational equality. Put another way, a key question for us is whether, at some point in the diffusion of DBS in society, people without DBS would be so deprived in absolute terms, or systematically constrained relative to what is possible for others, that they cannot live decent lives as human beings or as members of a particular society.

Aim 2 of our theory, which we have not examined in depth here, focuses on the profound injustices that arise from conditions of systematic disadvantage. However, not all inequalities confer advantages and disadvantages, and even those that do may not necessarily place others in a position of systematic disadvantage. What we are concerned about are the kinds of disadvantages that are so systematically oppressive that they prevent people from having decent lives.

Imagine a future in which so many people have DBS-enhanced memory that the unenhanced have no option but to take the lowest, most menial jobs. In such a case, the negative impact of not being enhanced bleeds into many if not all of the other dimensions of well-being. Without the enhancement, you cannot lead a self-determining life, you cannot understand the world around you well enough to be able to evaluate options and plan the way others can, you cannot assert your own interests in a meaningful way in the appropriate forums, and you cannot interact with others with a sense of your own comparable standing but instead feel only shame or embarrassment.

If not having been treated with DBS renders you like the crossing sweeper Jo to the wealthy landowner John Jarndyce in Dicken's *Bleak House*, feeling unworthy of

shelter in the other's person home even when deathly ill, then DBS for memory enhancement would fall within the entitlements of the sufficiency standard under our account.

Alternatively, imagine a future in which not having DBS is disadvantageous in a way comparable to not being able to attend an elite university. Although others with enhanced memory may do better in many arenas of life, much as the graduates of an elite university benefit from their superior connections and education, your information processing skills are still adequate for participation in the economic and cultural life of society as a moral and political equal. You are still able to navigate the social world sufficiently to determine the broad pathways of your life and to advocate for your interests. You do not feel, nor do others perceive you, as less worthy of respect and dignified treatment because you are not DBS-enhanced. In such a world, DBS for memory enhancement would fall outside what sufficiency would require, and would be ruled out as an entitlement.

Consider a further twist on the DBS example. Imagine that in affluent countries there is universal access to DBS enhancement and that the global affluent also avail themselves of the intervention. The comparative disadvantages of not being enhanced, which we further imagine are as oppressive as described in our first DBS scenario, now fall on the world's poor. Because of continued and escalating global interaction, these people are so systematically constrained relative to what is possible for others that they cannot live decent lives as human beings or as participants in the global order. In such circumstances, DBS enhancement would be required by our entitlement standard, transnationally as well as nationally.

In summary, the standards we set for identifying the goods and services that fall under the sufficiency threshold for health and the other dimensions of well-being are necessarily comparative. These standards are also necessarily dynamic, as dynamic as the creativity that fuels the life and engineering sciences towards technologies that for some seem almost beyond imagining. Which technologies are required for sufficient well-being, for a decent life, will change over time and are in part context specific. The answer to that question, and to when on the diffusion of innovation curve the demands of justice are triggered, cannot be given with algorithmic precision. But there is no necessary reason to conclude that these answers, or the approach to these answers, must be different when the technology is aimed at what some view as enhancing rather than protecting human biology, or even human nature.

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