

Biotechnology, Justice and Health

RUTH FADEN

Johns Hopkins Berman Institute of Bioethics

MADISON POWERS

*Department of Philosophy and Kennedy Institute of Ethics,
Georgetown University*

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 influenced 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.

INTRODUCTION

Deep brain stimulation, or DBS, is a biotechnology in which 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 as well, such as seizures and Tourette's, and also increasingly 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 and also about

the prospect that DBS might someday be used to enhance memory in those with no functional memory loss.

New biotechnologies like DBS have the potential to both dramatically improve human well-being and 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 assure 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 & 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 in 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 the example of DBS in these promising new memory applications.

PART ONE: A TWIN AIM THEORY OF JUSTICE

For us, claims in justice 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 an essential 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 or elements of human well-being that are among the 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 fully engage the thorny questions of just 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 at-

tachments 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 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 intent is that none is either at grave risk for the tyranny of deprivation or the threat of domination or oppression of others. Thus, among the defining concerns expressed in the positive aim of ensuring a sufficiency of well-being are two relational dimensions of well-being -- the good of living a self-determining life and the good of having a social standing involving the respect of others— where sufficiency requires nothing less than equality itself.

THE SYSTEMATIC DISADVANTAGE AIM

While the first aim focuses on the injustice of failures in the realization of a threshold level of the core elements of well-being, the second aim focuses on the injustice of creating and maintaining serious social impediments to sufficient levels of well-being. These impediments are wrong on our account even if some systematically disadvantaged individuals and members of disadvantaged groups manage to escape the adverse consequences to their well-being that most others so disadvantaged predictably experience.

PART TWO: SUFFICIENCY AND A DECENT HUMAN LIFE

Put another way, the first aim locates injustice in certain *adverse consequences* for well-being, while the second aim locates injustice in the *structural unfairness* of forms of social arrangement that distribute advantages and disadvantages in particular ways.

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. Indeed, these very points are familiar ones from within contemporary discussions of human rights where the aim is to articulate the minimum demands of a transnational standard of well-being that is neither implausibly high in what it would require of those upon whom such a duty might fall nor so low that it demands little more than bare subsistence (Nickel, 2007, 61-66, 98-103, 138-42; Buchanan, 2010).

In addition, our account of a decent life requires satisfaction of the moral demands of the relational egalitarian concerns expressed by a commitment to the goods of respect and self-determination, an emphasis which is also congenial with one strain in the human rights literature that expresses similar relational concerns. James Nickel, for example, suggests that there is a place in human rights for a variety of reasonable claims other than those for food, shelter, and education, including concerns for 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).

With the emphasis on self-determination and respect in our account of well being firmly in place, 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 & Faden, 2006, 138-41; Margalit, 1998). A decent life is not one in which someone is treated as less than a full member of the human community or as someone whose most vital concerns are 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 is one in which someone is not subjugated, marginalized, stigmatized, infantilized, or deprived of the full use of one's mature faculties.¹² 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 sufficiency bear on what counts as sufficiency in health. They also bear on the answers we give to questions of entitlements to health care goods and services instrumental to health sufficiency. We judge what is enough in the realm of 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 or sufficient health? And what instrumental goods and services, what resources, are individuals entitled to as a consequence?

Our answer to the first question is-- enough health for a decent human life. For us, this means enough health to live a full life course without significant 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. Any account of a decent human life must include living through all the stages of life without significant disability or dec-

1. Many of these points are developed in Mill's *The Subjection of Women*, which for us has been influential in our own thinking about what is central to well-being in view of a decent human life.

rement in health that can be reasonably prevented or mitigated, and pain or suffering that can reasonably be relieved.

At the same time, however, we are also far from what would be demanded for a maximally flourishing life, which would translate to a threshold of something like maximal health for all. Merely because the world's oldest person just celebrated his 115th birthday in Japan, or even because increasing numbers of people in many countries are now living into their 90s, it does not follow 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.

Importantly, 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 is going to depend on the implications of such access for where an individual stands in relation to her co-nationals.

It is implausible to think that the content of any entitlement to health-related goods and services, global or domestic, would be fixed for all time. Rather, the content is necessarily dynamic. What can be done to protect, restore and promote health and the other essential dimensions of well-being, is, as a function of technological innovation and diffusion, as well as cost and value, in constant flux.

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 to be cashed out 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 are caring for that person such as the loved ones of people with special needs.

The national entitlement may also include interventions that are higher cost or produce lower value, but only if in so doing there would be no negative impact on the availability of the good and services more essential to securing health sufficiency, or a sufficiency of the other core dimensions of well being, for all within its borders. 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" other goods and services that maybe even more necessary for sufficiency of well-being or a decent human life.

Also, it is important to emphasize 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 crowd out in which the pursuit of other valuable individual and social goods such as the arts and play and recreation would suffer.

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

We turn now to the question 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 again the example of DBS.

The possibility that DBS might become an effective treatment for memory disorders like Alzheimer's is extraordinarily important. Diseases and injuries that inter-

ferre with the cognitive processes that encode, store, and retrieve information 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's, what's, where's, and when's of their everyday lives, their suffering, and those of the people who love them, is enormous.

Much more work needs to be done to establish if DBS will prove effective in preventing or mitigating the ravages of Alzheimer's and other severe memory impairing disorders (Fell et al, 2012; Lee et al, 2013). However, assuming it does, and assuming that providing DBS to all relevant patients does not come at too high a price with regard 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 what we only hinted at in our initial discussion of the 2012 DBS epilepsy report. Some of the seven epilepsy patients in that experiment were NOT suffering from the memory impairment that sometimes co-travels with seizure disorders, yet *all* of them did better on the cognitive tasks when their brains were being stimulated. Assuming this line of research does succeed and the results are significant enough, it is a certainty that some people with normal cognitive function will seek DBS solely to get an intellectual edge or some other non-invasive neurotechnology such as transcranial magnetic stimulation.

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 & Bostrom, 2009; Harris, 2007; President's Council, 2003), much of it specific to cognitive enhancement including a limited literature on enhancement with invasive and non-invasive brain stimulation (Dresler et al, 2013; Kadosh et al, 2012; Hamilton et al, 2011). We engage here only one of those 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 enhancing biotechnologies is their potential to exacerbate or create egregious inequalities in human well-being. Some even hold that these technologies and social justice are on something like an inevitable collision course. Here we agree with Allen Buchanan's trenchant analysis that these criticisms are both overbroad, 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 does not itself necessarily pose fundamen-

tally 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 ever, do individuals become 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.

The second aim of our theory, which we have only signaled 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 confer advantages do 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 people cannot have decent lives.

Imagine a future in which so many people have DBS-enhanced memory such that, if you do not, your only options are to have the lowest, most menial jobs. *More importantly*, 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 in its disadvantaging effects more analogous to not being able to attend an elite university. Although others with enhanced memory maybe advantaged in many arenas of life, much as the connections secured and arguably the education received by graduating from an

elite university is advantaging, 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 have not been DBS-enhanced. In such a world, DBS for memory enhancement would fall above what sufficiency would require and would be ruled out as an entitlement.

Consider a further twist on the DBS example. Although we framed our original question in terms of national policy formulation, our theory and its implications extend as well to questions of global justice and access to new biotechnologies. Imagine that in affluent countries there is now 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 was just described, 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. DBS enhancement would now become 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 is fueling 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 prescribed with algorithmic precision. A theory like ours can only provide broad guidance as to what should be taken into account in specific policy contexts. But there is no necessary reason to conclude that these answers, or the approach to these answers, have to be different when the technology is aimed at what some view as enhancing rather than protecting human biology, or even human nature.

REFERENCES

- Buchanan, A.E. 2010: *Human Rights, Legitimacy, and the Use of Force* (New York, NY: Oxford University Press).
- 2011: *Beyond Humanity?: The Ethics of Biomedical Enhancement* (New York, NY: Oxford University Press).
- Dresler, M., Sandberg, A., Ohla, K., Bublitz, C., Trenado, C., Mroczko-Wąsowicz, A., Kühn, S., and D. Repantis. 2013: 'Non-pharmacological cognitive enhancement'. *Neuropharmacology* 64: 529-543.
- Fell, J., Staresina, B.P., Do Lam, A.T.A. Widman, G., Helmstaedter, C., Elger, C.E., Axmacher N. 2013: 'Memory modulation by weak synchronous deep brain stimulation: A pilot study.' *Brain Stimulation* 6/3: 270-273.
- Hamilton, R., Messing, S., and A. Chatterjee. 2011: 'Rethinking the thinking cap: Ethics of neural enhancement using noninvasive brain stimulation'. *Neurology* 76(187-193).
- Harris, J. 2007: *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton, NJ: Princeton University Press).
- Kadosh, R.C., Levy, N., O'Shea, J., Shea, N., and J. Savulescu. 2012: 'The neuroethics of non-invasive brain stimulation'. *Current Biology* 22:R108-R111.
- Lee, D.J., Gurkoff, G.G., Izadi, A., Berman, R.F., Ekstrom, A.D., Muizelaar, J.P., Lyeth, B.G., K. Shahlaie. 2013: 'Medial Septal Nucleus Theta Frequency Deep Brain Stimulation Improves Spatial Working Memory after Traumatic Brain Injury'. *Journal of Neurotrauma* 30: 131-139.
- Margalit, A. 1998: *The Decent Society* (Cambridge, MA: Harvard University Press).
- Mill, J.S. 1869: *The Subjection of Women* (London: Longmans, Green, Reader & Dyer).
- Nickel, J. 2007: *Making Sense of Human Rights* (Malden: Blackwell Publishing).
- Powers, M. and R. Faden. 2006: *Social Justice* (New York, NY: Oxford University Press).
- President's Council on Bioethics. 2003: *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (Washington, DC: President's Council on Bioethics). Available at http://bioethics.georgetown.edu/pcbe/topics/beyond_index.html (accessed 26th March 2013).
- Savulescu, J. and N. Bostrom. (eds.) 2009: *Human Enhancement* (New York, NY: Oxford University Press).
- Suthana, N., Haneef, Z., Stern, J., Mukamel, R., Behnke, E., Knowlton, B. and I. Fried. 2012: 'Memory enhancement and deep-brain stimulation of the entorhinal area', *New England Journal of Medicine* 366/6: 502-10.