

A Social Justice Framework for Health and Science Policy

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Introduction

The goal of this article is to explore how a social justice framework can help illuminate the role that consent should play in health and science policy. In the first section, we set the stage for our inquiry with the important case of Henrietta Lacks. Without her knowledge or consent, or that of her family, Mrs. Lacks's cells gave rise to an enormous advance in biomedical science—the first immortal human cell line, or HeLa cells. In the second section, we provide a very brief sketch of the theory of social justice with which we operate, a theory that explicates the demands of justice in terms of six essential dimensions of well-being, of which health is one, as is self-determination, and that is centered around twin commitments to the promotion of a sufficient level of well-being and the moral importance of addressing concerns about systematic disadvantage. We also consider the relation of our theory to concepts like the common good or public interest.

We then go on in the third section to address how our account of self-determination, particularly as it relates to insights from J. S. Mill, provides the theoretical backdrop for an important question in the ethics of health and science policy—whether some liberties matter more and why. Our core theoretical claim is that not all liberties and immunities from interference are on a moral par and thus that they do not all merit the same level of protection in public policy.

We close in the fourth part by illustrating how our theoretical apparatus frames and helps resolve concrete challenges about consent and privacy in health and science policy, using an example from HIV testing as well as the Henrietta Lacks case.

Henrietta Lacks and the HeLa Cells

In 1950, Henrietta Lacks was a poor, African American woman who had recently moved with her family to Baltimore, Maryland, from rural Virginia. At the time, Mrs. Lacks was a young mother of five with little formal education. She was becoming progressively more ill with pain in her lower abdomen and eventually went to Johns Hopkins Hospital for treatment, the only hospital in the region that at the time provided medical care to African Americans.¹ Unusual among American hospitals, it had been founded in 1876 by a bequest that specified that care be provided to the "indigent sick of this city and its environs, without regard to sex, age, or color" (Johns Hopkins, in a letter to the hospital trustees, 1873). Baltimore was, nevertheless, a Southern city. In keeping with the times, medical care, although provided to all, was delivered in segregated facilities.

In January 1951, Mrs. Lacks was diagnosed with cervical cancer. At the time, two physicians at Hopkins were on independent but related missions. Dr. Richard TeLinde, who was Mrs. Lacks's physician's superior, was determined to establish the relationship between noninvasive cervical cancer (carcinoma in situ) and invasive cervical cancer, and for that he needed tissue samples from women with cervical cancer. Dr. George Gey and his nurse colleague and wife, Margaret Gey, were also on a mission for which they needed tissue samples. Gey, who was head of the Tissue Culture Lab at Hopkins, had committed his lab to accomplish what had never been done—to grow a human cell line that would be immortal. Dr. Gey was asking all of his colleagues to provide him with tissue samples from any patient diagnosed with cancer in the hospital.²

On February 8, during Mrs. Lacks's first radiation treatment, which was standard of care for cervical cancer at the time, a sample was taken of her tumor and of healthy cervical tissue. According to *The Immortal Life*, these samples were removed not as part of Mrs. Lacks's clinical care but rather at the request of Dr. TeLinde for his research, and they were also made available to Dr. Gey.

By late February 1951, within weeks of Mrs. Lacks's first treatment and the removal of the tissue samples, it was becoming apparent that there was something special about Mrs. Lacks's cells. Inexplicably but astoundingly, they grew without end. These cells, now universally known as HeLa cells, became an essential tool of biological research, contributing almost immediately to the development of the polio vaccine, later to cancer therapies, and more recently to the HPV vaccine, which protects against cervical cancer, the disease that took Mrs. Lacks's life.

In keeping with the practice of the time, Mrs. Lacks's consent for the removal of the tissue sample, and for its use in research, was never obtained. In October 1951, Mrs. Lacks died in Johns Hopkins Hospital, never knowing of the extraordinary breakthrough in Dr. Gey's lab in that same institution. Her children did not learn of the existence of HeLa cells or that the cells were being bought, sold, and used in research until 20 years later (1973). It took many more years before they came to understand the meaning and impact of their mother's cells, and the identity of their mother as the source of the HeLa cells was made public without their authorization.

Dr. Gey and Hopkins did not profit in a direct financial way from this discovery; in keeping with the time, Dr. Gey literally gave HeLa cells away, for free, to scientists and laboratories all over the United States, and eventually all over the world. Gey and Hopkins did profit in other ways, of course, most notably in terms of reputation and professional standing. HeLa cells did go on to make, and still make, a great deal of money for some in the biomedical-industrial complex. Mrs. Lacks and her family have never received any financial compensation. Indeed, many in her family, most notably her children, remained profoundly poor and unable to afford consistent, basic healthcare over the years.

The story of Mrs. Lacks, her family, and the HeLa cell line raises many obvious, and still today unresolved, issues about how medical science with biosamples should be conducted. Every day in hospitals, thousands of biological samples are removed from patients in the course of countless diagnostic and therapeutic procedures. Should specific, informed consent from patients be obtained for each and every scientific use to which these samples could be put? Should patients benefit financially when, like Mrs. Lacks, their biological sample leads directly to

the development of a financially lucrative, marketed product? We turn to a theory of social justice that we think can be useful in addressing these and other moral issues raised by Mrs. Lacks's case.

The Twin-Aim Theory of Social Justice

For us, public health and biomedical science policies draw their foundational legitimacy—their ultimate justificatory structure—from the essential and direct role that health plays in human well-being, 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 theoretical objectives, the target of each barrel being morally distinct from the other, but strategically reinforcing. The positive aim is the improvement of human well-being, and in the special case of public health institutions, this aim is focally attentive to improving health as one of the most significant dimensions of well-being. The negative aim is to combat, whether by prevention or amelioration, the adverse effects on well-being caused by densely woven patterns of systematic disadvantage that, typically, have compromised or will compromise (if left unaffected) profoundly the health and other core elements of well-being for some persons and groups.

The positive 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.

There is much in our theory that may be congenial to those who are attracted to common good justifications for public policies. Our theory focuses on the well-being of populations, and also of groups within populations, and on the design of the social structures, including national and global institutions, that profess a commitment to the common good or public interest.

At the same time, however, it is important to emphasize that the idea of a common good is inherently ambiguous. We reject the familiar notion that the common good is a distinctive societal end, or an aim extrinsic to and not reducible to the contribution made to the good or well-being of its individual members. Systematic but sympathetic conceptual analyses of the very idea of such an end have shown just how difficult it is to find a plausible candidate for a common good of this sort. Consider, for example, Aristotle's remark that "the whole cannot be happy unless most, or all, or some of its parts enjoy happiness."³ The alternative, which we adopt, is to view the common good as an aggregative end, an end that has value because of the sum of the contributions made to the well-being of its individual members.⁴

Equally important is the fact that we place no normative priority on the good of the greatest number. The welfare of all matter—and none should be systematically disadvantaged in order to advance an aggregate communal interest or in the service of the maximization of any one element, or even of all the elements combined. Also, because we maintain that it is good for individuals to live in

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communities in which all can flourish—because we take a flourishing communal life to be a prerequisite for individual well-being—we reject any stark opposition between the good of individuals and common good, as well as the notion that health maximization alone, apart from other aspects of well-being, including respect and self-determination, is the exclusive consideration relevant to public health decisionmaking.

The Positive Aim and the Core Elements of Human Well-Being

The positive aim of social justice is defined in terms of a level of sufficiency of each core element of well-being. Although it is beyond our task here to engage the thorny questions of just how sufficiency for any element is assessed, 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, besides health and self-determination, includes four other core elements.⁵ Though these six overlap in terms of both determinants and effects, each is of independent and equal moral value.

- 1) The first element is personal security from actual physical and psychological harm as well as the threat of such harm.
- 2) The second element is the development of reasoning capacities, both for deliberation and choice and for the formation of beliefs and inferences regarding facts about the natural and social world.
- 3) The third element is respect of others, in which the central concern is that individuals be able to live under social conditions in which others judge and treat them as moral equals, and as persons worthy of the same sort of treatment any other person merits.
- 4) The fourth element involves the capacity to form and maintain personal attachments of various kinds with varying degrees of intimacy, commitment, and affective engagement.

That leaves health and self-determination.

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.

Because self-determination is the core element of well-being that is specifically important to discussions about consent, we spend more time on this element than on the others. In our twin-aim theory, the focal concern of self-determination is the ability of a person to exert some substantial, although not perfect or complete, control over her or his path through life. A self-determining life requires social conditions that can ensure that an individual is not merely the instrument of the will of others, or of social forces that she has had no role in shaping and that leave her without critical material or political standing.

The distinct value we associate with self-determination is the successful shaping of the broad contours of a life in ways that preserve the individual's independence from the effective control of others over the things that matter most in determining

the kind of life, as a whole, a person leads. Self-determination is thus not a simple function of having more privacy or more choices or fewer impediments to choice. What matters is that we have some significant say over the general course of our lives. 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.

Our use of the language of self-determination, rather than the language of autonomy, which is more commonly employed in medical and public health ethics, is intentional. Our emphasis is on the conditions for success in exercising control over the general shape of a life. Success thus entails both the capacities for self-direction and the favorable social and political conditions necessary for realizing one's most important choices in life, those that are most central to that shaping.

The Negative Aim of Social Justice

Much of the negative aim of justice centers around concerns about 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 cognitive development in relation to health, 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 emphasize that patterns of systematic disadvantage are not solely a result of greatly restricted opportunities for choice among mature, autonomous adults. When a sufficient level of well-being across multiple essential elements is not achieved in childhood, as is frequently the case with extreme poverty, the impact of deprivation at this critical stage in human development can result in what is effectively a life sentence of an unjustly low level of health, cognitive development, and other dimensions of well-being beyond that of self-determination disadvantages. Such deprivation at crucial stages of early life can affect all the essential elements of well-being so profoundly across a lifetime as to make later gains impossible.

Rethinking Liberty and Self-Determination

With this thin sketch of our twin-aim theory of social justice in mind, we return briefly to the question of whether all liberties are on a moral par and are due the same protection. The simple answer to that question is no, but the explication is not simple.⁶

J. S. Mill took on the issue by way of his famous principle of liberty. Mill's principle actually is comprised of two distinct parts. The first part is an absolute prohibition on certain coercive interferences (by the state or others), whether for

the benefit of others or in whole or part for the benefit of the person interfered with. On some matters the "individual himself is final judge."⁷ Neither the interests of others nor a calculus of comparative harm to others enters the equation. Mill notes that "over himself, over his own body and mind, the individual is sovereign."⁸

Whether Mill (or anyone else) can make a conclusive case for demarcating some domain of absolute sovereignty, fully insulated from all balancing of competing concerns, including concerns about the well-being of the person himself, is debatable. However, for our present purposes the important point is that Mill quite reasonably takes some liberties to be qualitatively different from others based on differences in the underlying interests they serve.

The second part of Mill's principle of liberty (the only part reasonably labeled the harm principle) confirms the centrality of a qualitative difference among liberties that warrants a difference in protection. The second part of the principle kicks in when the interests that ground claims of liberty are somewhat less important than those over which the individual is sovereign. These lesser liberties are still weighty enough to warrant a presumption in their favor, but they may properly be subject to some balancing against harms to "certain interests" of others.⁹ However, Mill is quick to note as well that only some actions are entitled to such a presumption. This leaves other liberties without the benefit of either absolute protection or a presumption in their favor.

Thus, Mill, in effect, can be read as drawing a tripartite distinction in the principle of liberty among (1) interests that ground sovereign liberty rights immune from any balancing, (2) interests that are sufficiently weighty to warrant a presumption in favor of liberty when balanced against the interests of others not to be harmed, and (3) interests that do not warrant a presumption in favor of liberty.

Mill says little about the interests that do not warrant even a presumption in favor of liberty. But we do know, for example, that Mill thinks that neither part of the principle applies to and thereby restricts consumer product regulation and mandatory hazard labeling, state registries for the purchase of dangerous substances, laws regulating product adulteration, worker safety and wage laws, and a whole host of contract and other marketplace regulations.¹⁰

Commentators who have not ignored this important exception have puzzled over why there should be such a distinction. Mill's arguments are in many places notoriously elusive, but we think that there are many illuminating clues, especially in *The Subjection of Women*. There, we find arguments for the special moral importance of the kind of choices that are central to the shaping of a life. He argues for equal liberties for women and men on the grounds that both have equal interests in making the kinds of life choices that matter centrally to being free from the control and domination of others.

The argument in *The Subjection of Women* thus suggests that what is at stake is not simply the value attached to making one's own choices whenever and however the opportunity might arise. Rather, it reinforces what Mill had in mind in *On Liberty* when he rejects the very idea of a liberty to sell oneself into slavery. By contrast, various forms of public regulation (for the sake of the public or common good) simply fall outside the scope of the principle of liberty. Indeed, other goods, including the public's health, matter greatly in Mill's view, in which the liberties at stake do not pertain to values of the sort we place under the heading of leading a self-determining life.

The lesson that we draw, in part from reflecting on similarities we see between Mill and our own account of social justice, is that it is critical in debates about health and science policies, including debates about biobanks and electronic health records, to avoid the error of treating all liberties, and the interests that undergird them, as on a moral par. In our view, these debates must start with a rejection of the (wrong) supposition that liberty is the sort of undifferentiated value that rests on interests that always warrant some preliminary tipping of the scales in their favor.

Health and Science Policy Reconsidered

Our twin-aim theory has a range of implications for debates about public health, science, and consent. Because we do not believe that all liberties are on a moral par, our focus is not on expanding or protecting choice or privacy, but on the more fundamental aim of protecting and promoting the ability of individuals affected by health and science policies to lead self-determining lives and to otherwise achieve a sufficient level of well-being.

For instance, reproductive issues have a greater impact on the overall shape of people's lives than the liberty to eat high-sodium foods. Health policies intended to influence people toward some externally defined reproductive ends affect some of the most important of all life choices. Although some may agree with Mill's own assessment that reproductive choices may not fall under his first category of interests that ground sovereign liberty rights immune from any balancing, at the very least, in our view, they matter sufficiently to warrant a presumption in their favor. All manners of state intervention with reproductive choice are morally worrisome, but this is not because of a simple presumption in favor of liberty *per se*; for us, this is because of the underlying value of self-determination that is at stake or implicated by interference with the particular liberty at issue in this instance.

By contrast, because the interests served by the liberty to consume high-sodium foods are, from the standpoint of self-determination, not weighty, any number of state policies, from the subtle placement of such foods in the back of a school cafeteria line to regulatory limits on sodium levels in processed or restaurant foods, may be justifiable.

It is important to note that, from the standpoint of our theory, arguments about the relationship between health policies and self-determination are often dependent on background social and scientific conditions that may be well beyond the ability of policymakers to alter materially, in the near term, and that change over time.

Consider, for example, the testing of women who were at high risk of being infected with HIV in the early days of the AIDS epidemic. Despite the utility of this information in interrupting maternal-fetal transmission, many advocated against making HIV testing a routine part of prenatal care for high-risk women in favor of a requirement of affirmative informed consent, because of the importance of various moral interests at issue for the women.¹¹ Targeting the subpopulation of women thought most likely to have a higher prevalence of HIV in practice often meant targeting the urban poor, and especially minority women of color. Although there was obvious public health logic behind the idea that more public health efforts ought to be directed where the health burden is greatest, that

logic ignored certain features of the social situation. The very women targeted for mandatory testing were more likely to experience greater stigma, loss of jobs and social support, domestic violence, and in effect, a loss of the ability to exercise control over their own fates, and all of the adverse consequences would have been realized in the context in which there was significant question about the prospect of direct medical benefit to the women themselves.

Today, the countervailing interests are viewed as less important, both because, with the advent of widely available effective treatments, the early detection of HIV infection is clearly in the medical interests of women and because the stigma and accompanying social risks associated with HIV have lessened. As a consequence, public health authorities have, correctly in our view, implemented HIV testing without express consent as the default position, including in facilities where most of the patients are poor women of color, usually with the proviso of a general disclosure that HIV testing is routinely preformed as part of prenatal care unless a woman expressly objects.¹² What is different is that what was once clearly a public health strategy that had great potential to undermine self-determination (and other essential elements of well-being) has given way to public health strategies that have clear potential not only for many women to have better health outcomes for themselves and their newborns, but for the enhancement of their prospects for leading self-determining lives. As the HIV example suggests, some social circumstances determine the capacity of any health or science policy or intervention to either promote or undermine self-determination. These considerations, rather than whether they are in some more narrow sense promoting or frustrating of liberty or privacy, are the more focal moral concerns that should guide policies about consent and governance.

Consider next, and finally, the case of Henrietta Lacks. As already noted, Mrs. Lacks's story raises important and unresolved policy and ethical issues about consent and about benefit sharing. Apart from formal biobanking initiatives, it is estimated that in the United States alone, the number of stored human tissue samples increases by at least 20 million each year, and we still have no resolution about how and by whom the use of these samples for research should be authorized or about what is owed to people when a marketable product results.

The publication of Rebecca Skloot's book about Henrietta Lacks and the HeLa cell line has generated an enormous discussion in the United States about how this research was conducted and how Mrs. Lacks and her family were treated. This discussion engages other components of our theory in addition to self-determination, such as respect, attachment, and affiliation, and most powerfully the concept of systematic disadvantage. Consider for a moment the impact of the story if all that happened to Mrs. Lacks had happened instead to a well-educated white man. The issues of consent and authorization would remain. Looking forward, these are issues that in our view need to be filtered against a self-determination analysis of the sort that we have sketched here.

From the standpoint of the second aim of social justice, however, other key questions to be asked as we vet alternative public policies include what impact each policy has on the most egregious of unjust inequalities, and whether the wider web of related social institutions, as well as the specific social policies under consideration, are sufficiently just to all affected. It is likely that Mrs. Lacks's family and friends did not benefit from some of the very scientific advances made possible by HeLa cells, nor did they experience the security of

knowing that, in the event of illness, they would be able to access these advances for themselves and their loved ones. As with so many, there was no guarantee that their lives would benefit from the science made possible by access to human tissues. For us, more than anything, Mrs. Lacks's story is about the inextricable relationship between the ethics of science policy—how we should govern biobanks and electronic health records—and the ethics of the healthcare system, about how the least of us live and about social justice. The experience of Mrs. Lacks and her family has added poignancy because it arises against the background of an unjust system of healthcare access, embedded in the systematic disadvantage of racism and entrenched poverty. The solution to problems of systematic disadvantage does not lie with the implementation of a process that, at best, allows a few isolated individuals to share in windfall profits, however welcome and arguably appropriate.

Notes

1. Skloot R. *The Immortal Life of Henrietta Lacks*. New York: Crown; 2010.
2. See note 1, Skloot 2010:30.
3. Barnes J, ed. *The Complete Works of Aristotle: The Revised Oxford Translation*, Volumes I and II. Princeton (NJ): Princeton University Press; 1984.
4. Murphy MC. *Natural Law in Jurisprudence and Politics*. Cambridge: Cambridge University Press; 2006:61–90, 168–76.
5. A fuller explication of each appears in chapter 2 of Powers M, Faden R. *Social Justice: The Moral Foundations of Public Health and Health Policy*. New York: Oxford University Press; 2008.
6. All citations of Mill are from Collini S, ed. *J. S. Mill: On Liberty and Other Writings*. Cambridge: Cambridge University Press; 2007. The arguments in this section are drawn from sections of a book manuscript in progress by Madison Powers on accounts of freedom in Mill.
7. See note 6, Collini 2007:77.
8. See note 6, Collini 2007:13.
9. See note 6, Collini 2007:75.
10. See note 6, Collini 2007:95.
11. Faden RR, Geller G, Powers M. *AIDS, Women, and the Next Generation: Towards a Morally Acceptable Public Policy for HIV Testing of Pregnant Women and Newborns*. New York: Oxford University Press; 1991.
12. See note 11, Faden, Geller, Powers 1991.