The Biopolitics of Bioethics and Disability

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Though bioethics emerged as a sphere of inquiry and application of moral and juridical principles less than a century ago, its rise and expansion have nevertheless been considerable. Not only has bioethics evolved into a popular subdiscipline of philosophy; many of its arguments and claims have also influenced work in the disciplines of medicine, the life sciences, and law. Furthermore, the arguments and claims of bioethicists have increasing currency in the political domain, affecting the design of public policy and law, the acceptance (or refusal) of forms of medical and scientific research, the identification of public funding priorities, and the inculcation of social values, expectations, and ideals. At one time limited to the relatively private and sacrosanct relations between physicians and the people they serve, bioethics has increasingly come to occupy a central position in the political discourse of technologically-developed societies. Neither the controversy surrounding some bioethical issues nor the political prominence and notoriety some bioethicists have gained, however, should obscure the nature of the causal relation between bioethics and politics. As Sheila Jasanoff has argued, political agendas have shaped the ways in which and the purposes for which bioethics has been used more than the other way around [1: 201].

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The rise and institutionalisation of bioethics ought to be regarded as a predictable product and tangible outcome of the governmental rationality that Michel Foucault referred to as "biopower" [2: 143]. Foucault defined biopower as the endeavour (usually by "authorities" of some kind) to rationalise the problems that the phenomena characteristic of a group of living human beings, when constituted as a population, pose to governmental practice. Such problems arise with respect to the birth-rate of a population, its health and longevity, sanitation and other conditions of its environment, and so on. Foucault pointed out that since the late eighteenth century these problems have occupied an expanding place in the government of individuals and populations. The new technology of power (biopower) which began to emerge in the second half of the eighteenth century takes as its object life itself, the life of the human being qua living being, that is, the life of the human being insofar as it is a living being [3]. Biopower is, in short, the strategic movement of relatively recent forms of knowledge/power that work towards increasingly comprehensive management of these concerns in the "life" of individuals and populations [4–5].

Foucault maintained that the continued preoccupation with juridical conceptions of power in modern political philosophy has obscured the productive capacity and subtle machinations of biopower. Juridical conceptions assume that the individual possesses power (as one would possess a commodity) in the form of inherent, inalienable rights, the transfer or surrender of

which, through a juridical act or a contract, constitutes a sovereignty. In Foucault's lecture of 17 March 1976 at the Collège de France he argued to the contrary that power is not something that is exchanged, given, or taken back, but rather is exercised and exists only in action [3]. Foucault also disputed the assumption that power is fundamentally repressive. Political theory, he argued, "must cease once and for all to describe the effects of power in negative terms: it 'excludes', it 'represses', it 'censors', it 'abstracts', it 'masks', it 'conceals'. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth" [6: 194].

Biopower's productive management of "life" has introduced a novel set of measurements, including the ratio of births to deaths, the rate of reproduction, and the fertility of a population. These aspects of the life of individuals and populations, together with a whole set of related economic and political problems, have become biopower's first objects of knowledge and the targets that it seeks to control. Foucault noted that as these phenomena began to be taken into account, a new type of medicine quickly developed whose main function was public hygiene, and whose institutions centralised its power, normalised its knowledge, and coordinated the care distributed under its auspices. There were campaigns to educate the public and medicalise the population. Charitable institutions and economically rational mechanisms (such as insurance, individual and collective savings, and safety measures) were established in order to deal with accidents, illnesses, and various anomalies. Since the phenomena with which biopower is concerned become salient only on a mass level, constants that pertain to the collective were established. Thus, biopower has facilitated the emergence of regulatory mechanisms whose function is to provide forecasts, statistical estimates, and overall measures and whose purpose is to intervene at the level of collective or group phenomena. In turn, these mechanisms have brought into being guidelines and recommendations that prescribe norms, adjust differentials to an equilibrium, maintain an average, and compensate for variations within the "general population" (a group of living human beings whose constitution *as* a "population" is in large part due to this form of power) [3: 238–263, 4: 4–5].

As a governmental rationality which aims to increase its efficiency by harnessing the vagaries of life, biopower normalises people in order to make them governable. Within the constraints of this normalising governmentality, certain differences amongst populations have been materialised and made perceptible as pathology, while the subjects who come to bear them are rendered as defective, are disabled, and signified as less than fully human. In short, they are the embodiment of a "problem" which must be resolved or eliminated. The practitioners of an institutionalised discourse (bioethics) which operates in the service of biopower must, therefore, grapple with the problem (or rather, problems) that such people seem to pose for that regime. These problems, that is, the problems that seem to arise from the troublesome phenomena surrounding such people are negotiated through deliberation on and invocation of allegedly objective and universal bioethical principles. Given the constitutive nature of discourse, these practices of negotiation and adjudication inevitably bring into being an array of discursive objects which actually reify those problems themselves. Some of the recent and most contentious of these discursive objects are "normalcy," "impairment," "enhancement" "quality of life," "end of life," and "futility," to name just a few.

Foucault convincingly argued that there is no power without resistance. Indeed, Foucault's argument from governmentality holds that the disciplinary apparatus of the modern state which materialises discursive objects through the repetition of regulatory norms also, by virtue of that repetitive process, brings into discourse and social existence the very conditions for subverting that apparatus itself. The regime of biopower in particular has generated a new kind of counter-politics which Foucault calls "strategic reversibility." In the terms of this counter-politics, this *biopolitics*, he noted, individuals and juridically constituted groups of individuals respond to governmental practices directed at life in increasingly intimate and immediate ways, by formulating imperatives and needs of that very "life" as the basis for political counter-demands [7–8].

Because power and resistance are inextricably entwined, during roughly the same period of time (though usually in very different contexts) in which disabled people and disability emerged as urgent problems for bioethicists, an international movement of disabled people coalesced, spurred on by the social gains of the women's movement, the black civil rights movement in the US, the lesbian and gay movement, and other "liberation" movements around the globe. This international movement of disabled people has

demanded an end to the discrimination and oppression that disabled people confront by virtue of the fact that their bodies, behaviours, identities, and modes of communication and motility do not conform to prevalent social norms, standards, and ideals, that is, norms, standards, and ideals that bioethicists (among others) uphold.

The interdisciplinary field of disability studies is in large part an outcome of this activism by disabled people and their allies. Since the Great Depression (and during the last thirty years in particular), they have challenged the received forms of knowledge produced about disability, pointing out the ways in which this knowledge reinforces and perpetuates the injustices disabled people have endured. Under the rubric of disability studies, these challenges now question the foundational assumptions of virtually every discipline, as well as the methodologies these fields of inquiry employ, the criteria of evaluation to which they appeal, and the epistemological and social positioning of the researchers and theorists invested in them.

Disability studies and antidisability activism are engaged in globally; hence, the conceptions of and responses to disability articulated in these contexts are grounded in (among other things) the disparate histories of local, regional, and national movements, juridical and administrative policies which, at this point in time, vary considerably from one jurisdiction to another, and theoretical, political, and professional allegiances which may be entrenched within some geopolitical spheres of the global discussion about disability. Despite the numerous differences between them, however, disability theorists (and activists) generally assume that, historically, bioethicists, policymakers, medical professionals, medical sociologists, and the nondisabled public have misconstrued the circumstances surrounding disability, how disabled people experience these circumstances, and what is required to ameliorate them. In short, disability theorists argue that although disability is a contingent social and political phenomenon, it has been misrepresented in medical and individual terms.

An example of this misrepresentation of disability is the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH), a classificatory scheme promoted by the World Health Organization from the early 1980s, which was regarded as an authoritative policy instrument by government officials and service agencies worldwide, until disability researchers and activists finally succeeded in forcing

major revisions to it some twenty years later. The initial ICIDH scheme has three dimensions: impairment, disability, and handicap. In this version of the ICIDH, *impairment* is defined as abnormality in the structure of the functioning of the body due to disease or trauma; *disability* is defined as the restriction in the ability to perform an activity considered normal for a human being; and *handicap* is defined as the social disadvantage that could be associated with either impairment or disability. Thus, this scheme establishes a causal relation between individual impairment (construed as a departure from human normality) and disability (conceived as restrictions in the abilities to perform certain tasks). In the terms of the WHO scheme, Lorella Terzi explains, the causes of disability are primarily attributed to individual biological conditions which depart from "normal human functionings" and which determine handicap in terms of disadvantage [9].

In 1990, British disability theorist Michael Oliver wrote that "the personal tragedy theory of disability" underpins this medicalised and individualised conception of disability. If disability is represented as a tragedy, Oliver remarked, disabled people will be perceived as the victims of some tragic happening or circumstance; furthermore, this perception will translate into social policies that aim to compensate disabled people for the tragedies that have befallen them. Oliver argued that disability should instead be regarded as a form of social oppression. If disability were defined as social oppression, he asserted, then disabled people would be recognised as the collective victims of an uncaring and ignorant society (rather than as individual victims of circumstance); furthermore, this definition would translate into social policies that aim to rectify and redress social injustice, rather than correct and compensate individuals. To counter the personal tragedy theory of disability, Oliver proposed a "social model of disability" which is based on the definitions that a group of UK activists—the Union of Physically Impaired Against Segregation (UPIAS)—introduced in 1976 [10: 4–11]. While the medicalised definitions of disability previously articulated were ultimately reducible to individual pathology, the UPIAS definitions locate the "causes" of disability within society and social organization. The UPIAS defined disability in this way:

> Disability is something imposed on top of our impairments by the way we are unnecessarily

isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability,' of people with such impairment. Thus, we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression [11, as cited in 12: 22].

Oliver and other "social modellists" claim that the radical innovation of the social model (and the UPIAS document from which it derived) is that it severs the causal relation between the bodies of disabled people (impairment) and their social circumstances (disability). As Oliver put it, "the social model insists [that] disablement is nothing to do with the body. It is a consequence of social oppression" [12: 35]. On the social model, he explained, disability is comprised of the innumerable aspects of social life that impose restrictions on disabled people, including personal prejudice, inaccessible public buildings, unusable public transportation systems, segregated education, exclusionary workplace arrangements, and so on. He pointed out, furthermore, that the consequences of these restrictions do not simply fall on random individuals as the personal tragedy theory implies, but rather systematically accrue to disabled people as a group who experience institutionalised discrimination throughout society [12: 33].

In other contexts [4–5, 8, 13], I have shown why one ought not to accept the foundationalist assumptions of the social model, nor its argument according to which there is no causal connection between impairment and disability. By drawing upon Foucault's argument that modern relations of power produce the subjects whom they subsequently come to represent, I have argued that the impairments which proponents of the social model claim to exist apart from disabling social arrangements are actually produced in accordance with certain requirements of those arrangements: that is, disability

precedes the idea of impairment, an idea that in turn provides the justification for the multiplication and expansion of the regulatory effects of disabling practices. That the discursive object called "impairment" is claimed to be the embodiment of some natural defect, deficit, or lack legitimises the fact that the constitutive power relations that define and circumscribe "impairment" have already put in place broad outlines of the forms in which that discursive object will be materialised. In short, the category of impairment emerged and, in many respects, persists in order to legitimise the governmental practices that generated it in the first place.

Notwithstanding the fact that proponents of the social model misunderstand the productive machinations of modern power, their arguments have historical importance insofar as they generated the social unrest that spawned a social movement. The discipline of philosophy has not remained unscathed by these forms of resistance. Within philosophy, the claims about disability which mainstream bioethicists advance have hitherto been regarded as authoritative, objective, rational, and disinterested. Such claims rely upon a biomedical conception of disability which construes it as a natural disadvantage, a property or characteristic of certain individuals, which can be eliminated through repair, correction, or prevention of such individuals. Given that disability is construed as a personal misfortune in this way, some bioethicists regard practices such as prenatal screening and testing, 'corrective' surgery, and physician-assisted suicide as moral imperatives, while others regard them as discretionary.

In the spirit of counter-discourse, a growing number of philosophers have variously challenged the authoritative status of this biomedical conception of disability and the claims derived from it, their alleged objectivity, and their putative value-neutrality. In particular, philosophers of disability and other disability theorists have argued that this biomedical conception misrepresents the actual nature and causes of disability. Philosophers of disability (and other disability theorists) also contend that insofar as bioethicists assume this conception of disability, they misunderstand what is required to rectify it. In this regard, they point out that the assumptions which bioethicists make about the character and causes of disability influence a great deal of what gets said about it in moral and political theories. To counter this biomedical understanding, therefore, philosophers and

theorists of disability formulate arguments which approach disability as a social problem, that is, a historically contingent product of exclusionary and oppressive contexts whose appropriate solutions are political, not biomedical, ones. In short, the work of philosophers and theorists of disability amounts to a thoroughgoing reconception of disability. This reconfiguration of disability is vital because it enables philosophers of disability (and other disability theorists) to highlight the marginalised social status of disabled people, to legitimise the subjective experiences of these people, and to foreground the social injustice and inequality they confront. Indeed, the contributions to this issue ought to be regarded as a biopolitical intervention of this sort.

In the lead article of the issue, Ron Amundson and Shari Tresky mount a "disability rights" critique of claims about disability which four prominent bioethicists make in their recent book *From Chance to Choice: Genetics and Justice* [14]. Amundson and Tresky's criticisms of the book in this context build upon arguments they have directed at it elsewhere.

Sara Goering's article, which contests the alleged objectivity of the judgements bioethicists make about disabled people lives, follows appropriately from Amundson and Tresky. By drawing upon the work of disability theorists, Goering undermines the claims of many bioethicists, according to which the quality of disabled people's lives is diminished and unsatisfactory.

In a sustained and eloquent critique of bioethicist Jeff McMahan's arguments about cognitive impairment, Eva Feder Kittay demonstrates that the subjective and lived experiences of disabled people and their loved ones and caregivers are often quite remote from the judgements bioethicists make about them. Kittay's article, which originally appeared in the journal *Ethics*, has been modified for this issue and is reprinted by permission.

Adrienne Asch, David Wasserman, and Jeff Blustein continue the discussion about cognitive impairment by asserting that bioethicists have neglected to consider the situation of people who live in segregated institutions. In a provocative departure from the position on segregated institutions taken by most disability theorists, Asch and her co-authors propose a set of recommendations for the improvement of such living arrangements.

Morgan Holmes uses disability theory and queer theory in order to that show the discourses of medicine and bioethics have detrimentally affected the lives of intersexed people. Through a critical analysis of claims made by bioethicist Carl Elliott, Holmes shows how medicine and bioethics collude with the regimes of heteronormativity and sexism in order to eliminate intersexuality.

Nikki Sullivan also employs the claims of queer theorists and disability theorists. Sullivan uses this work in order to examine how the desire for amputation has been conceived as one or another form of "disorder." In particular, Sullivan engages with accounts which cast amputation-related desires as symptomatic of a sex-based condition in order to highlight the assumptions such accounts make about normalcy, disability, and (un)desirability.

Feminist philosophers have long shown the inadequacies of traditional theories of autonomy. In an application of these feminist arguments to circumstances surrounding prenatal testing and physician-assisted suicide, Anita Ho argues that in order for bioethicists to recognise the value of disabled people's lives, the ideal of autonomy must be reconceived in relational terms.

Margrit Shildrick closes this intervention into bioethical discourse about disability with what she refers to as a "postmodernist" exploration of physician-assisted suicide (PAS). As Shildrick explains it, while bioethicists have neglected to think critically about disability in general, disability theorists themselves have truncated critical discussion about PAS in particular.

The most appropriate way to end this introduction is to acknowledge that the contributions to this issue have greatly benefited from the insightful and constructive refereeing performed by a number of my colleagues in philosophy, disability studies, cultural studies, and women's studies. I wish to thank all of them for their generosity and kindness in this regard. Special thanks are due to Ron Amundson, Susan Stryker, and David Wasserman for their extra assistance with the issue.

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