A Fatal Attraction to Normalizing:
Treating Disabilities as Deviations
from “Species-Typical” Functioning

Health Care as a Social Good

In the late twentieth century, (bio)medical ethics bifurcated into micro- and macrostudies, the former devoted to probing singular cases suffused with difficulties, the latter committed to finding some common good(s) to invoke so as to resolve hard as well as clear cases. Being clear about what kind of good health care represents, it was argued, enables us to decide who, in what circumstances, deserves it. To this way of thinking, while health is a personal good, health care is a social good. And it is not how to secure the former, but when to provide the latter, that is the challenge in morally difficult cases. Accordingly, macro-(bio)medical ethics developed an account of how to judge right and wrong in caring for patients, namely, by proposing what kind of health care, in what circumstances, a just society allocates.

Macro-(bio)medical ethics enthusiasts think that if we had a just system of health care, the right interventions would be evident. Once health care is cast as a social good, principles drawn from political morality will guide us in assessing the propriety and priority of various kinds of medical interventions. Just principles will enable us to see what should be provided for particular patients. It is the nature of justice to illuminate the difference between obligatory and merely beneficial interventions, that is, between necessary treatment and salutary enhancement.

The latter may be privileging or not, depending on how the patient is circumstanced relative to other people. But the former is always equalizing, suggests Norman Daniels in presenting his immensely influential theory, which is meant to place the provision of health care on the firm foundation of democratic values that, by tradition, inform our
public policy. What makes a medical intervention a treatment for Daniels, and what makes treatments equalizing vehicles is that they aim at preventing or remedying the disadvantages that people would otherwise suffer as the result of accident or disease.

None of us deserves the advantages conferred by accidents of birth . . . It is . . . important to use resources to counter the natural disadvantages introduced by disease . . . This does not mean we are committed to the futile goal of eliminating or “leveling” all natural differences between people . . . [But] health care has normal functioning as its goal: it concentrates on a specific class of obvious disadvantages and tries to eliminate them.

The notion of “leveling” that Daniels introduces here is a traditional theme in American political morality. Dissenting religious groups like the Quakers urged that society be arranged to show more respect for the commonalities of human nature, our essential humanity, than for artificial distinctions of class, caste, or role. Those committed to “leveling” were motivated by the conviction that all souls were equally valuable to God; therefore, all souls should have an equal voice in the community. The accidents of wealth and birth ought not to disadvantage people by limiting their opportunities for social participation.

Traditional leveling theories did not propose that all souls were identical, of course, but only that they have equal opportunity for community involvement and influence. Nor did these theories propose to eliminate the natural differences among people, only those accidental disadvantageous differences attendant on wealth and birth. Indeed, the argument for diminishing the importance assigned to wealth and birth (that is, to inherited rank) was that these socially constructed characteristics should not be allowed to obscure or impede the expression of natural talents and traits, the properties that naturally differentiate one individual from another.

In this tradition, Daniels’s policy proposes that health care should eliminate, to the degree possible, the disadvantageous adventitious differences that occur when poor health impairs physical, sensory, or cognitive functioning. People should not be leveled in every way, for they naturally differ in skills and talents; only artificially disadvantageous differences should be eliminated. One of Daniels’s important contributions to the traditional discussion is to suppose us to have become so proficient in the practice of medicine that the disadvantageous differences attributable to unrepaired poor health are artificial—as when people remain in
ill health due to an unjust system of distributing effective medical interventions. If the disadvantages associated with poor health are thus as much a social as a natural product, our “leveling” tradition urges that deficiencies in people’s functioning that result from poor health should be remedied so as not to diminish the opportunities their skills and talent would otherwise secure for them. Daniels writes:

We are obliged to help others achieve normal functioning, but we do not “owe” each other whatever it takes to make us more beautiful, strong, or completely happy. The uses of health care that most of us believe we are obliged to make available to others are uses that maintain or restore normal functioning, not simply any use that enhances our welfare. This distinction between the treatment of disease and disability and the enhancement of otherwise normal appearance or capabilities is reflected in the health care benefit packages of nearly every national health insurance system, whether public or mixed, around the world.

And as he concludes in another text, “If people have a higher-order interest in preserving ... opportunity, ... then they will have a pressing interest in maintaining normal species functioning by establishing institutions—such as health care systems—that do just that.”

On this (bio)ethical emendation to political morality, medical treatment has a public value because it is an instrument of the state’s commitment to protect all citizens equally against arbitrary disadvantage. Interventions that merely enhance the welfare or well-being of individuals in respects in which they are not disadvantaged do not have a similar public value.

The central function of health care services is to keep us functioning as close to normal as possible. Since maintaining normal functioning protects the range of opportunities open to people, by providing an appropriate set of health care services, we make a significant contribution to preserving equality of opportunity.

Treatments, then, are those interventions that are used to reduce or remedy whatever disadvantage is occasioned by abnormal functioning that is associated with ill health. Because treatments are so defined, they are necessarily equalizing, in the sense that to be treatments they must be aimed at preventing or rectifying disadvantageous functioning and, consequently, at reducing or eliminating a specific kind of disadvantage the patient has in comparison with normally functioning individuals. Treatments can be prospective as well as retrospective on this view. For example, as the purpose of vaccination programs is to prevent some
individuals from becoming disadvantaged by the sequelae of disease, to vaccinate children against polio or measles is to treat them.

Treatments are processes, however, and a process that has a definitive objective may not always succeed in reaching it. For example, it can be accurate to describe what we do in relation to our students as “educating them” even if some of the students are not educated. Similarly, treating someone may not always succeed in restoring that individual to the desired mode and/or level of functioning. But the key to a medical process’s being a treatment is the plausibility of our casting it as a procedure to eliminate a disadvantage by restoring functioning.

For example, breast reductions often count as treatments now that a convincing case for the disadvantageousness of very large breasts is made; for example, she can’t buy clothes that fit, she can’t run because of their weight, they make her an object of derision in the workplace. But we can imagine social contexts in which it is much harder to make this case. If women custom-made their own clothes, rarely ran (because society insisted it isn’t lady-like to run) and never, never pursued careers in the workplace (because fathers and husbands did not want women to work outside the home), it would be harder to argue that the breast reduction procedure remedies disadvantages rather than merely increases a woman’s comfort. For in that context women would not normally engage in the performances the procedure rehabilitates or restores. But this does not totally resolve the issue, for some women may desire to transform the roles females are permitted to adopt and so may argue that breast reductions remove one of the barriers to women’s assuming such roles. They might argue that in their case breast reduction is not merely a means of enhancing the welfare of large-breasted women with unfashionable preferences for comfort over sexual attractiveness; rather, it responds to a legitimate need to eliminate a social disadvantage.

Considerations such as these raised by the breast reduction procedure lead to questions about the neutrality of appealing to normal fashions of functioning. Sometimes, people who function in the normal fashion are, for that very reason, confined to roles that are disadvantageous and detract from their flourishing. This restriction has surely been the case for women in societies in which women have been assigned to disadvantageous roles on the ground that their normal fashion of functioning prohibited their achieving in more highly valued roles. Since the goal of treatment is to remove disadvantage, but normal fashions of functioning can be disadvantageous, why does Daniels believe that
(maintaining or restoring) functioning in a normal fashion is the standard for determining whether an intervention is a treatment?

**Normalizing**

Whether or not I am an individual whose disadvantage is reduced because I receive treatment, social arrangements providing for the reduction of undeserved disadvantage occasioned by physical, sensory, or cognitive dysfunction are for the public good, Daniels says, and thus for my good insofar as I am a community member. Daniels comments:

> I abstract from the special effects that derive from an individual's conception of the good. This level of abstraction seems appropriate given our search for a measure of the social importance for claims of justice, of impairments of health. My conclusion is that we should use impairment of the normal . . . as a measure of the relative importance of health care needs.7

Because treatment is a public good, the condition which occasions or invites it should be objective and independent of transitory social accidents, Daniels believes.8 What he takes to be the natural difference between normal functioning and functioning corrupted by illness or accident suggests to him a fixed and objective, and therefore an appropriately public, standard for ascertaining the occasions when treatment should occur. "Where we can take as fixed, primarily by nature, a generally uncontroversial baseline of species-typical functioning," we can show, he thinks, "which principles of justice are relevant to distributing health care services."9 Daniels thinks that the way the species typically functions constitutes a natural and therefore a neutral standard to which the public can assent.

First, all “people have a fundamental interest in protecting their share of the normal range of opportunities.”10 Second, maintaining “normal species functioning” is necessary to protect this high-order interest persons have in maintaining a normal range of opportunities: “Life plans we are otherwise suited for and have a reasonable expectation of finding satisfying or happiness-producing are rendered unreasonable by impairments of normal functioning. . . .”11 Third, and crucial to Daniels’s argument, is his assumption that normal functioning is natural and thereby neutral in that the criteria for determining what functioning is normal are biological rather than social. “The basic idea is that health
is the absence of disease, and diseases (I here include deformities and
disabilities that result from trauma) are deviations from the natural
functional organization of a typical member of a species. This step
of the argument is critical, for it is here that we are told why not
functioning as people typically do is disadvantageous. When disease is
the reason individuals do not function in typical fashion, their resulting
performances must be inferior to those that issue from individuals whose
natural functional organization has not been corrupted by disease.

Of course, this argument leaves open what counts as being diseased.
Daniels thinks that the line between disease and its absence generally
is noncontroversial and publicly ascertainable through the methods of
the biomedical sciences. Others argue to the contrary, of course. For
example, Susan Sherwin points out that some elements of women's
lives—for instance, menstruation, pregnancy, menopause, body size
and feminine behavior—have been medicalized and treated as diseases
because they have been viewed as disruptive of normal functioning.
In the same vein, genetic conditions that result in what we think is
inferior functioning are equated with disease. These examples suggest
that not disease but functioning in the normal fashion is the controlling
notion here.

John Rawls, on whose theory Daniels relies to scope out justice in
health care and other domains, gives us a political perspective on normal
functioning. He remarks:

[A] person is someone who can be a citizen, that is, a fully cooperating
member of society over a complete life . . . [F]or our purposes . . . I
leave aside permanent physical disabilities or mental disorders so severe
as to prevent persons from being normal and fully cooperating members
of society in the usual sense.

Here is an additional reason to think of a policy of normalizing
functioning as an instrument that secures the ends of democratic political
morality. For on the view that being a well-functioning individual is
critical to performing the social responsibilities of citizens, normalizing
is seen as qualifying functionally defective individuals for citizenship by
repairing them so they can execute the usual social interactions and
sustain common social responsibilities. To do so they must conduct
themselves normally and be able to comply with other people's natural
expectations of them. For whoever cannot perform competently as a
cooperating and contributing and, therefore, an equal, social partner
is fully neither citizen nor person.
The Right to (Normalizing) Treatment

The prescription is clear: although interventions that enhance a patient's functioning so that it departs from what is normal may be advisable for the patient when they enhance the patient's welfare, only interventions that normalize command a broader social warrant. That is because normalizing interventions restore or maintain individuals as cooperative, contributing citizens.

To understand what is at stake, we should notice that at least two aspects of functioning, the mode and the level, affect whether the performance of a function is normal. A function's mode is the way it is accomplished. To illustrate, the normal mode in which we execute the function of reading a document is by seeing the text. This function can be executed in other ways, for instance, tactually if the text is brailled, aurally if the text is scanned into a computer with a voice output screen reader. These alternative or adaptive modes may support a normal level of functioning. If the individual is adept, she may still read at normal speed and comprehension. Or she may function in the alternative mode above or below the normal level. According to Daniels, restoring individuals who have suffered impairment of functioning through illness or accident to the normal mode and level of functioning takes priority. If treatment fails, the next step is adaptation.

One important function of health care services... is to restore handicapping dysfunctions (e.g., of vision, mobility, and so on). The medical goal is to cure the diseased organ or limb when possible. When a cure is impossible, we try to make function as normal as possible, through corrective lenses or prosthesis and rehabilitative therapy. But when restoration of function is beyond the ability of medicine per se, we begin another area of services, nonmedical support services. It is important to notice that this system gives mode of functioning precedence over level of functioning. On it, we first attempt to restore the patient's ability to function in the customary mode, seeing or walking or hearing the way other people do. Afterward, if a cure proves impossible, we apply prostheses—corrective lenses, artificial limbs and physical therapy, hearing aids, and lipreading lessons. These prostheses may restore the patient to the typical level of functioning (or enhance it, remember the Bionic Man) but not (quite) to the normal mode: lipreading requires that those engaged in dialogue face each other, artificial limbs demand both stump and prosthesis maintenance, corrective lenses must be put on and removed.
Parenthetically, Daniels complains that social support services are allocated fewer resources than restorative treatment. Given Daniels's account up to this point, his preferred explanation is curious. He hypothesizes:

Yet for various reasons, probably having to do with the profitability and glamor of personal medical services and careers . . . as compared with services for the handicapped, our society has taken only slow and halting steps to meet the health care needs of those with permanent disabilities.¹⁷

It is odd for him to think that the reason society does not provide sufficient social support services is because doing so is not sufficiently personally profitable or glamorous for professionals. His own account provides a more persuasive explanation, namely, that the initial response to defective functioning, which consequently has first call upon resources, is restorative treatment. On his own account, normalizing interventions do and should take precedence over interventions with any other kind of impact because their outcomes are assigned a higher social or political value.

This priority is because normal functioning appears to be a firm and impersonal, yet compelling, goal, whereas we have no reliable standard of what counts as satisfactory if an individual does not function normally. Normal functioning is a clear standard as well, Daniels supposes, because to determine what normal function is, we need only observe the natural functional organization of human beings. This task, he says “falls to the biomedical sciences . . . since claims about the design of the species and its fitness to meeting biological goals underlie at least some of the relevant functional ascriptions.”¹⁸ So neither the predominant functional modes nor the modal functional levels are artificial, he thinks. Because the functioning that typifies a species seems so expressive of its nature, species-typical functioning appears to be a self-justifying standard, nature’s way of deducing how we ought best to conduct ourselves given what kind of creature we are.

Further, what could be a more modest and natural expectation of individuals than the prospect of functioning as their species typically does? Given these considerations, all individuals equally are found to have a natural stake in social arrangements designed to prevent or repair anomalous conditions that interfere with species-typical functioning. Concomitantly, relatively few individuals would have an interest in preserving or promoting any specific functional anomaly or singularity.
So it seems as if the broadest-based public support very naturally will
go to social arrangements that reduce whatever anomalies or singularities
hinder adherence to the species-typical functional standard.

The protean character of two of the notions pivotal to Daniels’s
argument, namely, those marked by the designations “natural” and
“normal,” is striking. Absent the suggestion that these are virtually
interchangeable characters, in that our normal fashions of functioning
are those that are natural rather than acquired, there would be no
obvious connection between normalizing modes of functioning and
equalizing opportunity. For there is nothing unusual in equally healthy
people experiencing vast differences in the opportunities available to
them, nor in people in different states of health enjoying similar scopes
of opportunity. But our species has evolved a natural functional organiza­
tion so well-suited to realizing these goals, Daniels thinks, that an
individual’s falling away from this organizational standard by not func­
tioning normally cannot help but diminish his or her options for desir­
able achievement.

What apparently is important here is not actualized opportunities.
Rather, what is supposed to be equalized is the amplitude of options
that each individual has available for achieving our species’ biological
goals. It might seem, then, that nature determines what normal species
functioning is (a biological premise) and in doing so specifies the mode
and level of functioning individuals need to exhibit if they are to enjoy
meaningful equality of opportunity (a social conclusion).

Yet when we probe more deeply into Daniels’s account of just
health care, we find that it is a social rather than a biological value that
informs and validates reparative interventions. Indeed, it is not even a
sociobiological value, for rather than surrendering individual benefit to
the species’ collective evolutionary good, the value to which Daniels
appeals is simply an extension of the liberal sociopolitical commitment
to preserving equal access to opportunity for the individual.

Daniels’s standard is biological, but the principle that implements
it clearly is not. For biology tends to eliminate truly dysfunctional
individuals, not repair them. The principle that advises us to restore
people’s normal functioning through health care is also not an expression
of an impersonal sociobiological drive of individuals to maintain their
species. At most it is an intersubjective principle with the potential to
unify the personal interests individuals have in maintaining a competitive
position. It suggests that we should be suspicious of claims that there
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is a biological mandate that accredits policies of normalizing people by restoring them to typical or familiar modes and levels of functioning.

“Normalizing” has a passionate component, of course, namely, our tribal preferences to congregate with individuals like ourselves. But our attraction to the company of our counterparts, which can be intense, is not usually thought to justify a public commitment to allocate resources to repair those who do not measure up. Simply avoiding or excluding those who fall away from the common standard is the usual concomitant of our passion for congregating with those who most resemble us. The difficulty with thinking of a policy of normalizing as a component of democratic political morality becomes even more evident when we notice that normalizing is sometimes privileging rather than equalizing. For instance, interventions that help some individuals more closely approach species-typical functioning may deprive, disadvantage, or otherwise reduce opportunities for individuals who function normally already. And, as we saw when we considered the value of breast reductions, making normalizing our policy can also be unfair if it worsens the position, or otherwise oppresses, the very individuals whose functioning it purports to repair by, for instance, depriving them of anomalous but effectively adaptive alternative modes of functioning.

We should be wary of policies that cloak privileging certain fashions of functioning in the mantle of the “normal.” Normalizing then is not the self-evidently right thing to do. Nor can we justly allocate health care without careful attention to the circumstances of whoever is normalized.

What Is Being Normal?

How useful is the concept of normalizing in warranting medical interventions considered case by case? Whether, in fact, there is much clarity about what normalizing is raises a second kind of concern about its compatibility with egalitarian ends, for there is a tendency to equivocate to a dangerous degree as to the meaning of this admittedly circumstantial standard. In “The Meaning of Normal,” Phillip Davis and John Bradley comment:

Medicine uses the word normal to express ... various meanings. ... In medicine, normal can refer to a “defined standard,” such as normal blood pressure; a “naturally occurring state,” such as normal immunity; ... “free from disease,” as in a normal pap smear ... “balanced” as in a normal diet, “acceptable” as in normal behavior, or it can be used to
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describe a stable physical state. In all these meanings . . . normal is used to describe an “ordinary finding” or an “expected state.” But medicine allows another meaning . . . that differs significantly from the ordinary. [M]edicine has come to understand normal as a “description of the ideal.” . . . Defining the norm as an ideal leads to significant problems. . . . Disease and ill health are a normal part of the human condition. The constant pursuit of health . . . leads easily to blaming those who bear the burden of illness. . . . More important . . . are the problems that result from defining variation from the ideal as “abnormal.” . . . Accepting the ideal as the norm begs the question of how uncommon something must be to be considered abnormal.\textsuperscript{19}

Current practice assigns pathological conditions the role of being signifiers of unhealth. But because it is not cost-effective to intervene wherever pathology occurs—that is, to conduct an all-out campaign to normalize all parts of all people—current practice takes a further conceptual step by identifying some departures from the norm as incapacitating, while others are tolerated as benign. Davis and Bradley observe: “When the ideal is taken as the norm, variation becomes defined as disease—an especially peculiar circumstance insofar as much variation has no particular clinical significance or biological consequence.”\textsuperscript{20}

Christopher Boorse suggests that it is usual on current practice to assess departures from the norm as warranting intervention if they cause death, disability, discomfort, or deformity.\textsuperscript{21} Interventions are made not on the ground of the rarity of the condition but rather its disruption of function. But while death indubitably is incapacitating, disability, discomfort, and deformity need not always be so. To define such conditions as necessarily dysfunctional and consequently as demanding intervention begs the question.

Surely, any measure used to sanction intervention should distinguish what is not normal and thereby harmful from what is not normal but merely unusual or anomalous. This is to avoid justifying every culture’s every intercession into anomalies regarded by that culture as pathological. For instance, for the Punan Bah of Borneo, the birth of twins is a greater social disgrace than the birth of a spastic, blind, or retarded child. It is so socially disturbing and disadvantageous a condition that it is also dysfunctional, for after twin births, one twin always dies (unless it is given to another family living distantly enough to achieve the concealment of its twinhood).
Normal Quality of Life

To distinguish such prescientific practices to remove anomalies from modern medical practices to abate defects in individuals, Dan Brock very usefully attempts to say more about the damage that departures from being normal can do. In *Life and Death* (1993) Brock correctly eschews offering an absolute standard for knowing when medical intervention properly remedies abnormality.

The dominant conception of the appropriate aims of medicine focuses on medicine as an intervention aimed at preventing, ameliorating, or curing and thereby restoring, or preventing the loss of, normal function or of life. Whether the norm be that of the particular individual, or that typical in the particular society or species, the aim of raising people’s function to above the norm is not commonly accepted as an aim of medicine of equal importance to restoring function up to the norm. Problematic though the distinction may be, quality of life measures in medicine and health care consequently tend to focus on individuals’ or patients’ dysfunction and its relation to some such norm.22

How does dysfunction present itself as a diminution of quality of life? Brock observes: “At a deep level, medicine views bodily parts and organs, individual human bodies, and people from a functional perspective.”23 But what one must go on to grapple with is the difficulty of connecting, let alone commensurating, different kinds or levels of functional descriptions. An increasingly familiar component of medical judgment, so-called quality of life scales are meant to quantify well-being to determine for what and on whom health care dollars are best expended.

Brock cites such a “Quality of Well-Being Scale”24 to illustrate a discussion about containing high-cost but low-benefit treatments. Of almost equal weight on the scale are what are designated as the patient’s physical activity level, namely, how competently the patient executes the performances of daily living, and (assigned just slightly more importance) the patient’s functional level, that is, what the patient achieves through engagement in daily life performances.

But these rankings do not reflect the subtleties of what can be achieved despite impairment. In the physical activity category of the scale Brock cites, mobilizing by walking, albeit with a feeble gait, ranks higher than using a wheelchair to be mobile. But which mode actually
facilitates mobility more effectively is not nearly as clear as this scale makes it out to be. For while wheelchair users are more limited in the types of sites they can access, they exceed the customary level in respect to the speed at which and distance from where they travel to those sites. Individuals who mobilize by walking can climb into many more types of sites but only those they have the time and stamina to reach.

The physical activity category assesses the modes individuals adopt to perform a function and then assigns the patient a rank that reflects the degree to which his mode of functioning diverges from the customary mode. Walking very feebly more closely resembles our customary mode of mobilizing than wheeling very vigorously, so the individual who uses the former mode is assessed as enjoying a higher quality of life than the individual who uses the latter. On the other hand, the functional category addresses interactions between the patient and the environment. For whether someone who uses a wheelchair can get into a car or use public transportation, for instance, is as much a question about the availability of appropriately designed vehicles as it is about the patient.

This abstracting from complex differences between kinds of limits suggests that the scale is more responsive to the mere fact of an individual's being limited than to how functionally devastating or benign the limit might be. We should discount any scale that arbitrarily fixes the relative effectiveness of different modes of performing any function, any scale that equates what is most common with what is best, and equally any scale that illegitimately naturalizes such rankings by appeal to biological imperatives. For mechanically aided functioning is not necessarily inferior to unassisted activity, no more is driving twenty miles to be disparaged as the crutch of subnormal hikers, and no more than manually signed communication is categorically inferior to speech. In general, we should mistrust any scale of well-being that purports to measure life’s quality by comparing modes of functioning in a way that obscures how modes that are not the common fashion can nevertheless be fully functional.

Moreover, we should distrust any summative process that commensurates fixed and variable elements while disregarding the contexts to which the latter are relativized. The degree to which either personal or environmental limitations result in social limitations—that is, prevent an individual from normal social achievement like having a family and earning a living—is the outcome of complex interactions between the individual’s limits and the limits of his or her environment. It is therefore
difficult not only to predict the degree to which, but also to comprehend the process whereby, physical or environmental dysfunction leads to social dysfunction.

Brock himself recognizes that even serious physical limitations do not always lower quality of life if the disabled persons have been able or helped sufficiently to compensate for their disabilities so that their level of primary functional capacity remains essentially unimpaired; in such cases it becomes problematic even to characterize those affected as disabled.25

As the individuals Brock describes just prior to writing this passage are persons without arms and legs, this remark is revealing. If their eating, driving, painting pictures, raising a family—the functions of a good life that Brock portrays them as achieving—makes it problematic to describe them as disabled, then underachieving must be part of the definition of disability. And if being disabled is tied so firmly to lowered achievement, then even very marked deviation from species-typical functioning has only circumstantial connection to disability.

For it is far from clear that deviations from normal functioning mean either lowered productivity or decreased quality of life. Far from being the natural way of conducting ourselves, the modes of functioning that typify our species may merely be ways of doing things that are preferred by the dominant classes and to which we have therefore become accustomed. To the extent that this preference is the case, policies of normalizing, however well-intentioned, threaten not to equalize but to preserve existing patterns of functional dominance and privilege, a problem exacerbated by an absence of clarity in the practice of medicine in regard to establishing what is normal.

A Social Instrument for Normalizing

Accordingly, we need to clarify the nature and consequences of a public policy that gives expression to a mandate to normalize, an inquiry that I propose to pursue by exploring an analogous sphere, the domain of education. At least two reasons compel us to consider what we can learn from comparing analogous practices in education and health care. First, our current public policy intersects the two domains by legislating entitlements to preventative health education and rehabilitative special education within the public educational system. Indeed, a surprisingly large amount of what Daniels describes as basic health care needs are served by the public education system. Given that it is an egalitarian
value, equalizing opportunity, that ultimately justifies the allocation of health care on Daniels's view, he is relatively expansive in delineating what is needed “to maintain, restore, or provide functional equivalents (when possible) to normal species functioning. These include adequate nutrition and shelter, safe and unpolluted living and working conditions, preventative and rehabilitative personal medical services, and nonmedical personal (and social) support services.”

Using public education to deploy preventative, curative, and rehabilitative health care services is, of course, a very familiar practice. During the past century, day and residential schools in this country have, to give some examples, enforced preventative vaccination policies; promoted safe, sanitary, unpolluted, and tobacco-free living; ensured that children are given the basic principles of nutrition; instructed students about maintaining the health of their reproductive systems; identified and referred children in need of reparative care for vision, hearing, and other impairments; and offered rehabilitative speech, psychological, and other therapies, or adaptive education for blind children or deaf children, on their premises. Second, Daniels himself not only finds the analogy between educational and medical benefit apt but relies on it to argue for social support for (universal) health care:

[T]here is an important analogy between health care and education. Both are strategically important contributors to fair equality of opportunity. Both address needs that are not equally distributed among individuals. Various social factors ... may produce special learning needs; so too may natural factors, such as the broad class of ... disabilities. ... Educational needs, like health care needs, differ from other basic needs ... Both at the national level and in many states, legislation to meet special educational needs ... is justified by reference to the opportunities it protects.

Daniels construes education as a reparative technology, while Brock describes it as an enhancement technology. The difference between their views lies in whether, as Daniels thinks, our educational priority should be to teach all children the knowledge and skills normally required to be participating, contributing citizens, or whether, as Brock has it, our educational priority should be to advance the widest array of children's cognitive abilities so as to nourish their different talents and give each appropriate personal opportunities for flourishing. In education as in health care, then, there is a question about the priority to assign to engendering normal functioning.
The Ascendancy of the Normal

In this regard, the battles that raged for nearly a hundred years about how best to educate deaf children provide an opportunity to assess the benefits of giving priority to normalizing. In the late nineteenth century, educators of the deaf bifurcated into two camps, one that passionately supported and one that vehemently opposed educating deaf children in the language of manual signs. Each charged the other with protracting the dysfunctionality of deaf people and consequently with unfairly constricting their opportunity. At the heart of this debate lay another divide, namely, an unbridgeable chasm that separated two very different beliefs about the relationship between biology and opportunity. As Douglas Baynton writes in *Forbidden Signs: American Culture and the Campaign Against Sign Language*: “The real battle (over sign language) was fought on a . . . rarefied plane, encompassing such questions as the larger purposes of education in a democratic and industrializing society . . . and the locus and character of cultural authority in America. Indeed, occupying a central place in the fight was a late-nineteenth century debate over the nature of nature itself.”

That deaf individuals talk by means of manual signs has been recognized since antiquity. Plato refers to this mode of communicating in the Cratyllus (422e). In the early part of the nineteenth century manual sign language schools were established to equalize deaf people’s access to the Word, understood to be the conveyance of that moral and religious knowledge which is the goal of human imagination, intelligence, and understanding. Because manual signing was thought to rely on natural symbols that were self-interpreting, Sign was believed to engage the intelligence directly and lucidly, and to stimulate the moral sense. Sign therefore was the instrument to repair deaf people’s dysfunction and permit them to develop to greatest perfection. America followed Europe in becoming fascinated by signing. Teachers were imported to systematize and disseminate the gestural communication used by the deaf in this country.

Manualists considered deaf people to be a singular class, distanced from the transient fashions of speech and therefore less corruptible, out of the ordinary, remarkable, unique. Citing such eighteenth-century sources as Daniel Defoe and Denis Diderot, Lennard Davis writes in *Enforcing Normalcy: Disability, Deafness and the Body* that, for different reasons and in different respects, both the blind and the deaf were often thought to exhibit certain heightened and purer sensibilities than the
ordinary person. Far from being roleless, deaf people were assigned a special place in the eighteenth- and early nineteenth-century imagination. But, as Baynton observes, “by the late nineteenth century, naturalness as an ideal was being challenged and eventually was not merely defeated but colonized by the competing ideal of ‘normality.’” For one thing, naturalness had lost its status as a trait independent of and superior to the artifice, convention, and craft characteristic of social organization. “This intellectual and indeed moral shift in American culture was crucial to the reversal in attitudes toward sign language and the deaf community,” Baynton adds.

An 1884 speech by oralist Alexander Graham Bell shows how naturalizing the preferred behaviors of the dominant class propelled a program of normalizing, where this meant conforming the behaviors of deaf children to those of the hearing majority: “I think we should aim to be as natural as we can. I think we should get accustomed to treat our deaf children as if they could hear. . . . We should try ourselves to forget that they are deaf. We should teach them to forget that they are deaf. We should . . . avoid anything that would mark them out as different from others.”

By 1899 we find the President of Amherst College, John Tyler, folding the mantle of science around these normalizing practices. Tyler assured a convention of oralists that America would “never have a scientific system of education until we have one based on . . . the grand foundation of biological history. . . . [T]he search for the . . . goal of education compels us to study man’s origin and development.” (This is not unlike the appeal to science Daniels makes in saying that biological science shows us how the natural functional organization of the species is a design “that permits us to pursue biological goals as social animals.”) Such scientifically based or biologized education would maintain the functional strategies that seemed to place speech higher on the scale of evolutionary development than the expressive gestures of lower primates. The political morality of the time made it a moral and social obligation to increase the opportunities of both deaf signers and gesticulating foreigners by repairing them, a duty which a scientific system of educating them in the language and communication behaviors of the dominant class could help discharge.

It is important to understand that the fundamental division here is between competing ideas of what organizes a well-ordered society. The eighteenth-century’s ideal of individualized moral perfection had given way to an ideal of communal or social participation by people who
functioned dialogically in common in the public sphere. Where once
text. Language's highest function had been to engage individuals with ideas
understood as transcendent sources of right belief and right conduct,
now its most important use was to engage people with one another in
productive commercial and civic interaction.

Arguing against the idea that deaf people could flourish with a
language of their own, an oralist insisted: "To go through life as one
of a peculiar class is the sum of human misery. No other misfortune
is comparable to this." This thought typifies the shift of priorities from
personal to social improvement, and the correlated elevation of the
importance of collective over idiosyncratic individualistic identities.

This urge to create fair opportunity by leveling the players rather
than the playing field is a theme which has come more and more to
dominate American egalitarianism over the past hundred years. What
is striking is that systematically "normalizing" how deaf people communi-
cate (and many other rehabilitation strategies) may amplify anomalous
individuals' opportunities by making them more fit to pursue these,
but concomitantly may make them less able to perform alternatively
or adaptively. By devaluing alternative or adaptive modes of functioning,
the policy transgresses liberal political theory's requirement that the
state remain neutral between different citizens' ideas of the good life.
Oralism's defense of its violation of this dictum was that, until deaf
individuals communicated and consequently contributed in the normal
mode, they could not be qualified for the protection due citizens.

Normalizing is played out in both medical and educational programs
that intervene to repair or restore or revise members of nondominant
groups so they qualify as citizens. In education, normalizing has been
expressed as a mandate to assimilate the children of immigrant families
to the dominant culture, and to impose the practices and preferences
of males upon females. In being presented with arguments for norm-
alizing deaf children, the public was invited to decide whether the
management of "deaf schools" should be awarded to hearing people
who promised to assimilate deaf children. By allocating resources to
educational techniques intended to normalize deaf people, public policy
imposed a conception of the good under which they did not flourish.
We need to ask now whether there are some people who may not
flourish, or whose well-being will be compromised, if normalizing
similarly warrants and consequently guides the allocation of resources
that go to health care.
A Cost/Benefit Assessment of Normalizing

Normalizing has costs. If maintaining or restoring normal function is of such public significance that a system of benefits is made available for this purpose, it is hard to resist supposing that those whose functioning is anomalous ought to acknowledge the system by assigning the same priority to being restored. Baynton reminds us: “Oralism meant that many deaf people had access only to limited or simplified language during the crucial early years of language development.” 37 For fear they would fall back to communicating in a more convenient but “abnormal” or “unnatural” way, deaf children were often not taught to write unless they had mastered intelligible speaking. This practice left a legacy of reduced literacy among deaf people.

Interventions that reduce rather than expand already limited functionality surely extract too high a price, but such is the history of oralism in the education of the deaf. “Oralism failed,” Baynton concludes, “and sign language survived, because deaf people themselves chose not to relinquish the autonomous cultural space that their community and language made possible.” That is, for many people who do not hear, the opportunity of communicating fully within a limited group appears to be more satisfying, more equalizing and more meaningful than the opportunity of communicating in a limited way with the larger community. This is not to say that all deaf and hard of hearing people make this choice, but merely to point out that the alternative to normalizing often is not a limitation of full functioning but merely a limitation in the expanse of environment in which one functions successfully.

Tribalism, our partiality for interacting with those most like us, undoubtedly influences us to assign preeminence to (the appearance of) normalcy. But to the degree it corrupts the positive balance of benefits over personal and public costs, serious questions about whether the policy of normalizing compromises fair opportunity rather than promotes it must be addressed.

The Canadian Health Care system’s intervention in the cases of children born with missing or shortened limbs because their pregnant mothers took thalidomide illustrates this last point. In their treatment, appearing more normal was the priority, so much so that large public sums were expended to design dysfunctional painful prostheses which actually decreased their dexterity and mobility. They could walk with these, but only painfully and slowly. Reminiscent of the oralist ban on
signing, they were forbidden to roll or crawl, although these modes offered much more functionality, at least within their home environments.

The direction of resources to fund artificial limb design and manufacture rather than wheelchair design was influenced by the supposition that walking makes people more socially acceptable than wheeling does. As the children became independent adults, less vulnerable to the aggressive elements of institutionalized health care, they discarded the dysfunctional prosthetics in favor of wheelchairs, some made to their own designs. Here is another case (among many such examples I could adduce) in which the tyranny of the normal cost anomalous individuals to sacrifice an effective level of functioning at the alter of social preference for a particular mode of functioning, and in so doing compromised rather than equalized their opportunities.

We should not underestimate the coercive potential of policies that validate a particular mode of functioning by directing resources to efforts to restore that mode. When oralism dominated in schools for the deaf, deaf children could either try to lip read and speak, or have no education at all. For the Canadian children with no usable lower limbs, mechanical limbs were the only mobility option offered because policy directed the resources to institutions that designed and engineered limb-like prostheses, not wheelchairs. More generally, then, to commit public policy to restoring individuals to species-typical modes of functioning diminishes public recognition of, and consequently resources for, alternative modes of functioning.

So far, we have seen that normalizing equalizes opportunity primarily for those who can be maintained in or restored to the image of the dominant group. But no natural biological mandate nor evolutionary triumph assures that the functional routines of this group are optimally efficient or effective. Rather, the members of this group have the good fortune to find themselves in a social situation that suits them.

For others, there is the choice of limited functionality in an ordinary environment, or ordinary functionality in a limited environment. How much opportunity need be absent from the former alternative, or sacrificed by the latter, depends upon how expansive the nonhostile environment can be made. Replacing staircases with spiral ramps for wheelchair users, adding captions to televised programs for deaf viewers, alt-tags to computer icons so that the screen readers used by people who are blind can identify them, all these make the constructed environ-
A Fatal Attraction to Normalizing

ment less hostile to and more inclusive of people who function in anomalous, alternative, or adaptive modes.

The main ingredient of being (perceived as) normal lies in finding or creating social situations that suit one. Contrary to Daniels's claim, normalizing is no self-warranting process that deserves the allocation of resources because it furthers democratic values. For individuals with disabilities, for example, such values are better advanced by developing social environments accustomed to people like one's self. The record of their history does not support assuming that broad social or moral benefits accrue to normalizing interventions. The attractiveness of warranting health care interventions that maintain/restore normal functioning on the ground that they are instruments of justice therefore appears to be much dimmer than the initial enthusiasm of macro-(bio)medical ethics for normalizing suggests.

Disability, Self-Respect, and Lowered Quality of Life

Nothing said so far should be interpreted to mean that interventions to maintain or restore familiar modes of functioning never enhance individuals' welfare. But as we have seen, no clear difference in social benefit, or strict difference in obligation, separates these interventions, ones Daniels would call treatments, from interventions that enhance already average functionality. Then why is functioning normally of such value that maintaining or restoring this level becomes a decisive standard?

A critical component of a good quality of life, Dan Brock says, depends on each of us measuring our capacities and capabilities favorably against the standard of normal human functioning. That is, whether we function normally or not influences how we rate ourselves in comparison to others and consequently affects our confidence and self-esteem. This observation suggests that the paramount benefit of being normal is to maintain the psychosocial well-being of tribalism.

Brock may well be correctly describing a self-reflective process our current cultural standards promote. But this is not sufficient to defend the process as reliable or otherwise reasonable. We have seen that normal functioning is hardly a firm and reliable mark of the quality of our performance. Indeed, it is so fragile a standard that Brock worries about how easily a program of genetic intervention might shatter it. Brock, and others, are alarmed by the potential genetic intervention has for disrupting our confidence in the standard of normalcy.
First, if we manipulate genes to raise the level of performances that typify our species, any pretense that typical functioning is a natural rather than manipulated standard vanishes. Heretofore, a social structure that privileges some people to control communications and construction to suit themselves has determined what modes of functioning are considered normal. Henceforth, a social structure that privileges some people to influence genetic research and the allocation of genetic interventions might determine what levels of functioning become normal. What is feared is that our current confidence in a firm and impersonal, because natural, standard of normality will be undermined by a new and widespread recognition of seemingly normal functioning as being merely the artificial expression of the interests of whichever members of our species are positioned to deploy technology.

Will such an eventuality constrict rather than enlarge opportunity? Applying genetic technology that increases disparities of access to opportunity initially appears to be inconsistent with a democratically informed health care system, regardless of how much personal welfare the applications might bestow. Consequently, justice appears to advise constraining, or even prohibiting, these important broad applications of genetic technology.

For instance, genetic intervention could result in improving how some people function, so that someone who performs at a level that was comfortable for his species-average parents might find that the naturally good genes he inherited from them are surpassed by great genes installed in his competitors as a compensatory or even as a privileging measure. Constraining applications of this technology so that no individual can acquire an abnormally large number of desirable characteristics may seem advisable. But it is hardly an implementable policy, for the desirability of many of our characteristics is itself provisional and dependent on environment. Whether, and how, adding specific characteristics benefits the recipient—whether it privileges, equalizes, or just makes one more comfortable—must be decided with regard to the context in which the patient will function.

Brock is also concerned about whether, as we come to understand genetic structures accurately enough to identify the potentially anomalous functioning consequent on every species’ member’s inheritance, some members of the species will find themselves devalued by their own futures. Although performing splendidly at the time, they will be labeled, and consequently marginalized, as being at greater risk than others of deteriorating function. So, for instance, those at risk of Alz-
A Fatal Attraction to Normalizing

heimer’s would be rejected as mates by whoever wanted the services of a spousal caretaker, while employers desiring to keep medical insurance costs down would not hire individuals genetically disposed to developing various kinds of cancer.

With the widespread use of genetic testing, he worries:

People who feel healthy and who as yet suffer no functional impairment will increasingly be labeled as unhealthy or diseased. . . . For many people, this labeling will undermine their sense of themselves as healthy, well-functioning individuals and will have serious adverse effects both on their conceptions of themselves and the quality of their lives. 39

Notice that, at this point, the idea, rather than the reality, of nonnormal functioning has become the signifier of whether someone is equally well off, or is advantaged or disadvantaged in comparison to others. This observation suggests that it is one’s psychosocial rather than physical functioning that is most vulnerable to variations from accustomed states or normal prognoses—that is, to deviations from what is typical of our species. Brock describes how this occurs: “Generally it is when we have noticed an adverse effect or change in our normal functional capacity that we contact health care professionals and begin the process which can result in our being labeled as sick or diseased. . . .” 40 Brock thinks an adverse outcome of a genetic test could trigger this same process, though deterioration in physical functionality has not been and perhaps never will be manifested. Here being labeled as likely to become nonnormal initiates psychosocial processes that themselves are dysfunctional. The perception of being disadvantaged thus precedes and causes, rather than follows upon, dysfunction.

So the standard constructed to identify who is disadvantaged itself becomes the facilitator of disadvantage. Applying genetic technology then is merely the occasion, not the cause, of an unjust constriction of opportunity. It need not be categorically constrained for fear it will do so. For notice now how the disconnect between actually functioning differently and being disadvantaged has opened even wider. In the case about which Brock worries, individuals are functioning normally but are disadvantaged by having a significant potential, perhaps never to be actualized, for anomalous functioning. Here the social convention of the sick role, rather than the realities of effective performance, determines what modes and levels of functioning are advantageous, indifferent to advantage, or disadvantageous.

The prospect of increasing the power of the standard of species-
typical functioning to consign individuals to the sick role undoubtedly is alarming. However, it is not the standard, but the science that could extend its applications, that is typically attacked. So Adrienne Asch and Gail Geller express their concern that “the Human Genome Initiative could turn out to make ‘species-typical functioning’ a guide to joining or remaining part of the human community.”

To counter these worries about genetic research, we should turn from policies of normalizing to approaches that make us more receptive to alternative ways of functioning. The strategy of protecting against discrimination those who function differently, are genetically disposed to function differently in future, or are perceived as functioning differently is of great help here. The 1990 Americans with Disabilities Act offers one strategic example; another is the recent stream of legislation protecting patients against disclosure of the results of genetic testing.

“Black, Yet White: a Hated Color in Zimbabwe”

If we initiate proper protections against the tyranny of the normal, genetic technologies that greatly increase our repertoire for adaptation have a far greater potential for promoting justice than for compromising it. They have this potential because they open new avenues for social compensation. But our discussion so far advises our approaching this technique for improving disadvantaged individuals with some caution. To illustrate, I want to consider the wisdom of changing the pigmentation of individuals whose birth color is a disadvantage.

There is wide agreement that resolving the American color problem by turning African Americans white is unjust. But our democratic intuitions about turning white people black are much less assured. In the United States, albinism occurs in about one out of every twenty-thousand births; in some parts of Africa, in one out of every one thousand to two thousand. “In Africa, far more than on any other continent, [albinism] is a lifelong curse. . . . As white-skinned men in a black society, they are shunned and feared as the products of witchcraft,” writes Donald MacNeil Jr. in a front page story in the New York Times. Should white Africans resident in Africa be turned black if this is the normal pigmentation of the members of their tribe? If normalizing is the instrument of justice, we have a pressing reason to help them do so.

Let us suppose that emerging genetic technology will soon permit us to intervene. Let us also suppose that for biological, cultural, and economic reasons, including the widespread incidence of the genetic
factors that contribute to the condition (one individual out of seven is a carrier of a recessive gene for one or another of the types of albinism), screening to eliminate the birth of people with albinism in Africa proves impractical. Let us suppose, too, that we develop a series of relatively uncomplicated gene therapies so that neonates with albinism are enabled to produce the requisite enzymes or other factors related to skin-color that their type of albinism makes them lack.

Does a just health establishment owe it to African infants with albinism to widely distribute this therapy, making it as available as, for instance, are a variety of treatments such as the polio vaccine, or cleft-lip and club-foot corrective surgery? It is imaginable that such a policy would find opposition, on grounds of fairness, in the very sites where albinism is most common, namely, in those parts of Africa referred to in the *New York Times* article. For in those places, according to the article, people with albinism are thought of as a model minority who are seen as being more intelligent and successful than their black brothers and sisters.

Although their intelligence tests fall in the same range as their sisters’ and brothers’, as a group, Africans with albinism develop higher capabilities, possibly as an adaptation to their physical limitations. It is hypothesized that their light-sensitive and deficient vision, and their sun-sensitive skin, restrict them to contemplative rather than active lifestyles, which encourage them to be more studious and which qualify them for more education and more respected and better remunerated careers. By having fewer opportunities, they are more easily focused on ones that would be more advantageous for anyone. Parenthetically, Africans with albinism may benefit to some extent economically from the respect traditionally accorded those thought to be powerful witches. In regard to the entire spectrum of opportunities for social participation, Africans with albinism participate less in tribal or communal opportunities but participate at a higher than normal rate in those that are educational and economic.

**Normalizing, What Priority?**

Given these realities, ordinarily pigmented but poor Africans could easily think that it would be unfair to expend scarce resources to increase pigmentation in their brothers and sisters with albinism. This group does well enough as it is, and so treating the genetic anomaly that creates their disadvantage in regard to some forms of socializing might
enhance the already highly competitive level of functioning of this successful minority. On the other hand, because they overcome some of their natural disadvantage, do Africans with albinism then not deserve additional social support, namely, a program of reparative gene therapy? Are they owed nothing to remedy their social isolation?

So is turning white skin black any more pressing a social responsibility than deploying surgical skills to bring prodigiously down-turning or up-turning noses into conformity with the fashionably modest nose, or filling acne scars with collagen? Because there may be no firm answer as to whether a health care intervention does or does not level social advantage, we often cannot deduce from principles of justice whether a medical intervention effects treatment or enhancement. Consequently, even in a just system—indeed, especially in a just system—this distinction is unlikely to guide us in determining what should be provided for particular patients.

Of course, health care’s primary mission is to keep us functioning. That Africans with albinism are ostracized socially argues for compensatory intervention regardless of whether, all things considered, they are a group that already succeeds economically. But what kind of intervention is most just remains an issue. To justly liberate group members’ many talents, its members could be altered to better satisfy the expectations that pervade their social environment. On the other hand, altering the environment to better support their flourishing may correct their disadvantage equally well.

Neither the personal and social costs, nor the logistical difficulties attendant on each alternative, can be ignored in the course of developing compensatory policies. In the event biological alteration is the preferable policy, neonates with albinism would have to be identified and their families convinced to accept intervention. Arguably, the increase in physiological benefit—reducing vulnerability to the ravages of the sun—added to the significant social benefit of eliminating a provocation for discrimination, might sway the balance. On the other hand, social arrangements for distributing protective clothing and suntan oil might also adequately improve personal welfare, but only if the social environment is organized to embrace those who appear deviant, if it is, in fact, an environment reformed so as not to turn anomaly into dysfunction.

This last consideration remains too much neglected by prominent strategists of health-care justice. As we have seen, our normal modes and levels of functioning are, to an extent that often goes unrecognized, socially relative constructions rather than independent biological facts.
Adjusting the environment so anomalous individuals can better flourish can be as compensatory as leveling them. Moreover, enhancing individuals or their groups by magnifying their exemplary performance in some domains can, under some circumstances, sometimes compensate for there being barriers to their performance in other domains of functioning. Wherever strategies that equalize the amount of opportunity individuals have available rather than homogenize the kinds of opportunities they can access are feasible, there is even less reason to suppose that restoring anomalous individuals to normal modes of functioning is a better instrument of justice than enhancing the effectiveness of their anomalous modes.

In positing justice as the regulatory ideal of health care, macro-(bio)medical ethics initially proposed a deductive model on which principles of justice would inform our picking out and prioritizing those medical interventions that further equality. Interventions that qualify as treatments because they aim effectively at restoring normal function were, on this model, to take precedence in the allocation of resources. As we have seen, however, endorsing maintenance or restoration of normal functioning as the standard for allocation can itself, all too readily, prolong disadvantage. Macro-(bio)medical ethics must therefore overcome its fatal attraction to normalizing in order to open itself to other strategies for advancing justice.

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NOTES


34. Baynton, *Forbidden Signs*, p. 36.
Enhancing Human Traits:
Ethical and Social Implications

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