

ISUMA (Newsletter)

Genetics, Normalcy and Disability

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ABSTRACT

Since genes are increasingly seen as determinants of health, we are faced with decisions about whether, or how to alter them in order to ensure that people are healthy, and able to participate in society. Our ideas about what makes a person “normal” in terms of health play a pivotal role in these decisions. Within policy discussions, it is crucial to recognize that genetic testing and intervention have the potential to further stigmatize and devalue the disabled on the basis of variations and differences in our bodies.

THE “NORMAL” is perceived to be an objective way to think about human beings, a means to represent or quantify “what is” on the basis of statistical averages.[\[1\]](#) However, the “normal” also contains often opaque and unquestioned value judgments, and is used to represent what is right, and desirable.[\[2\]](#) Often, when normalcy is invoked, there is a blurring of the distinction between fact and value, confusing what is, with what should be.[\[3\]](#)

Our notions of normalcy tend to equate identity with the body. Those notions of normalcy inform medical procedures performed on our bodies—from the straightening of teeth and bones, to the treatment of illness, to the correction of mental disorders—that are aimed at making a person “healthy” and more “normal.” Genetic knowledge, it is argued, can be used to explain a significant number of diseases, conditions and behaviours. The gathering and use of genetic information is shifting the clinical focus from external to internal determinants of disease.

Disease is associated with abnormal or mutated genes. The result is a dramatic narrowing of the parameters of health, in which “human difference is viewed as predominantly a medical or biological matter.”[\[4\]](#) Those who oppose the new genetics caution that “[t]he concept of the geneticized self endangers the basic human rights of persons with ‘bad’ genes since they are then defined out of humanity and potentially outside the boundaries of moral responsibility.”[\[5\]](#)

Within a democratic notion of citizenship, each individual is assumed to possess the characteristics of self-reliance, efficiency and competitiveness. As a result, an idealized version of the “average person” has come to exist, while those who do not possess these privileged characteristics are considered abnormal—often because of the perception that they are not healthy. In this sense, the disabled are seen as both political and medical challenges, and problems. To meet the ideal of democracy, the disabled must be included and granted the right to full democratic participation. However, insofar as they are dis-abled, they are perceived to contribute less to, and require more from society. “Difference,” manifested as disability, is seen as problematic and undesirable within constructions of normalcy, and increasingly within public policy. “Normalcy” is used to rationalize medical attempts to eradicate our differences, and to render all bodies alike—healthy and interchangeable—as sameness is perceived to be the foundation of equality. The study of normalcy as it relates to the new genetics, illustrates both the potential benefits and dangers resulting from the application of technologies to our bodies. Throughout history, bodies have been categorized on the basis of various socially constructed standards. In the early 19th century, artistic and linguistic renderings of the body contrasted the “ideal”—a body unattainable by human beings, inhabited purely by the mythological—with the “grotesque,” the bodily condition of all mortal members of a culture.[\[6\]](#) The grotesque encapsulated the bodily imperfections and commonality of “the people.” At this historical moment, human variability was not measured with reference to the norm *per se*, however, the

grotesque can be seen as signifying the ordinary, “normal” body. The notion that the ideal body could only be inhabited by gods prevented the social fragmentation and hierarchical categorization of human beings by rendering the possibility of bodily perfection unattainable. Thus, human variability was not further subcategorized beyond the grotesque, and disability did not yet exist as an operative social construct.

With the modern quest for progress came the desire to impart order into “naturally” occurring social and biological phenomena such as illness, disease and deviant behaviour. The concurrent rise of industrialization and statistical analyses resulted in the development of the concepts “norm” and “average.” Both were applied to the body, predominantly by means of the study of disease. “Normalcy” brought about both the possibility of social control, and implications for moral responsibility, particularly since the health of a population was believed to be required for the advancement of society.[7] Biology and medicine equated the “normal” with the study of health. The normal healthy state was thought to exist in opposition to the pathological. As such, health was theorized as the mean between excesses and deficiencies in the body. Deviations from the normal state of health were construed as abnormal and as “disease.” Falling squarely within the category of those considered to be abnormal and of ill health were “the disabled.” “Bodies inscribed by disability displace the cultural ideal of the positive, coping, well-situated, fine carried, erect and proper social body.”[8] Thus, disability is a function of the concept of normalcy. The constructs are premised upon the assumption that the majority of the population is, and should be, physically capable. As a result, inherent in the concept of disability is the idea that a pervasive medically describable paradigm of human physical ability or mastery of the body is possible.[9]

The modern quest for progress has been characterized by competing beliefs about the uses to which the “normal” and the concept of normalcy should be put. One situates the normal as “the right and the good.”[10] Within this understanding, the norm is held out as a position to which all should aspire. The normal is a cultural and biological imperative, which represents the average, both physically and morally. It also is a means to justify and preserve the status quo. The “average man” [*sic*] was constructed based upon the average of all human attributes in a given country.[11] Thus, the average body became the ideal against which all others are measured. All variations within bodies became characterized in terms of variation from the normal state. “The concept of a norm... implies that the majority of the population must or should somehow be part of the norm.”[12] It also creates the existence of deviations from that norm — or, when applied to the body as the site of identity, the presence of “abnormal” persons within a population. In addition to being a quantitative marker of human variability, the normal is a powerful normative tool that is used to determine and rationalize the extent to which certain persons fall *outside* the boundaries of moral responsibility.

A second construction of normalcy perceives the normal as representative of mediocrity, a human condition that signals—if not demands—the need for improvement and excellence.[13] This conception focuses on the amelioration of differences, characterized as imperfections, in the human body. From here, the assumption that a population can *be “normed”* readily developed, and was put into practice.[14] The danger inherent in this understanding of the norm is that it has historically been accompanied by the desire to eradicate all deviations therefrom. This is evidenced by the chilling reality that “almost all the early statisticians were eugenicists.”[15] “[E]ugenics became obsessed with the elimination of ‘defectives,’ a category which included the ‘feeble-minded,’ the deaf, the blind, the physically defective, and so on.”[16] Statistics and eugenics were developed in concert. Over time, the concept and practice of averaging, as it applies to the human body, has been modified. Rather than using the mean to represent “the norm,” a purposeful shift was made to the use of the median.[17] When thinking about human traits, for example, this allowed the extremes—such as tallness, or high intelligence—to represent the distributions of a trait. The average was no longer the norm—the norm became signified by upper extremes of a trait or characteristic. This avoided the “middling of desired

traits.”[18] The result was the redefinition of the concept of the “ideal” in relation to the general population, and the construction of normalcy based on higher-end extremes of specific “desired” traits.

The new ideal of ranked order is powered by the imperative of the norm, and then is supplemented by the notion of progress, human perfectibility, and the elimination of deviance, to create a dominating, hegemonic vision of what the human body should be.[19]

Normalcy is necessarily implicated within policy discussions about the appropriate actions to be taken in order to ensure that people are healthy and able to participate in society. “Species-typical normal functioning” is an expression of normalcy based on statistical articulations of the “normal body.” It describes the relationship between health, disease and an individual’s share of the normal opportunity range.[20] In order to inform medical and political knowledge and practice, species-normal functioning implicates particular understandings of impairment, equality and opportunity, and renders specific proclamations about the nature and desirability of disability. Articulations of normal species functioning secure the social positioning of the disabled as abnormal and deviant. The bodily interventions proposed on this basis reflect the tension between the competing constructions of normalcy.

Species-typical normal functioning is based on the notion of the normal healthy body, in which “health is the absence of disease, and diseases (including deformities and disabilities that result from trauma) are deviations from the natural functional organization of a typical member of a species.”[21] In concert with normative positions about health, it has been used to frame dominant ideas about disability. Those who “discuss the importance of health care, urge accident prevention, or promote healthy lifestyles...” on the basis of normal species functioning “...do so because they perceive a certain level of health not only as intrinsically desirable but as a prerequisite for an acceptable life.”[22] This paradigm of health has the potential to translate very quickly into the devaluation of people affected by chronic illnesses and disabilities, as it assumes that *to be disabled is to be unhealthy*. Health has been linked to an individual’s range of opportunities as a result of what many disability activists consider erroneous assumptions within medically oriented understandings of the impact of disability on life. “First, that the life of a person with chronic illness or disability is forever disrupted... [and] second, that a disabled person experiences isolation, powerlessness, unemployment, poverty or low social status [as] these are inevitable consequences of biological limitation.”[23]

The assumption that we should strive to remove the barriers to opportunity that arise *due to disease* is being fuelled by geneticization. Traditional notions of equality of opportunity, based on socio-economic standing, race or ethnicity, are being expanded by genetic knowledge to include genetic makeup, viewed as a social asset that determines one’s ability to compete for resources. The implication is that all persons should begin with equal initial “social and natural assets” and that genes themselves are social assets. Here, “the conception of equal opportunity... relies upon the idea that there is an obligation to devote some social resources to preventing or correcting undeserved differences in initial social or natural assets that result in some persons’ suffering significant limitations on their opportunities—limitations so serious as to interfere with their having reasonable prospects of a decent life.”[24] In other words, it is assumed that “in order to count as a fully co-operating citizen, one must have an ‘opportunity range’ which is compatible with ‘normal species functioning.’”[25]

“Genetic” discourses of normalcy reiterate the notion that the ability to pursue opportunity is related to, if not determined by, genetic composition. Proponents of the new genetics aim to “relieve human beings, *all* human beings, of the burdens of genetic disease.”[26] Their universalistic goal is to remove suffering and limitations to opportunities through the application of the genetic knowledge achieved through “scientific progress.” The OTA (U.S. Congressional Office of Technology Assessment) says that “individuals have a paramount right to be born with a *normal, adequate hereditary endowment*.” [27] Based upon this assertion, many proponents

of genetic intervention adopt normal species functioning in order to assert that there are likely to be cases that “*require* interventions to correct or prevent genetic defects, including interventions that involve direct modification of genes or modification of their expression through the application of genetic science.”[28] This position is based upon “justice,” which is understood to arise through the creation of equal opportunity by modification of our bodily “limitations.” It is believed that, “genetically based disabilities, like other disabilities, impair opportunity.”[29] Since information obtained through genetic testing offers insight into whether a fetus will be “normal” *prior to its birth*, some assume that we can and should alter that body in order to improve upon the future person’s ability and opportunities. This demonstrates how disability is viewed as an extremely undesirable form of human variation not compatible with life satisfaction—more so than sex, sexual orientation or race, which are morally frowned upon as characteristics amenable to genetic intervention.[30] Proponents of the new genetics state:

[W]e place most of our hopes for genetics on the use of antenatal diagnostic procedures, which increasingly will let us know whether a fetus is carrying a mutant gene that will seriously proscribe its eventual development into a functional human being. By terminating such pregnancies, the threat of horrific disease genes contributing to blight many family’s prospects for future success can be erased.[31]

Disabilities are framed as limiting both opportunity and welfare—“even when they are not so severe that the lives of those who have them are not worth living, and even if those individuals do not literally suffer as a result of their disabilities.”[32] As a result, upon the detection of “severe” disabilities by prenatal tests, it is believed to be morally acceptable to “*eliminate*” a fetus. This position is informed not only by the present lack of genetic treatment, therapy or cures for most genetic diseases, but also by the understanding of health that privileges the norm of “ability.” Disability, however, is more than a question of health. It is a proclamation about societal views about difference and our willingness to embrace differences. To do so would be to put forth alternative views of justice and equality—in which vague notions of “impairment” based on descriptions of alleged physical or mental deficiencies neither define the disabled, nor justify their subordinate social status.[33]

The standard of the “normal” body assumes that the majority population is, or ought to be, physically capable. “Disability” carries with it such a powerful imputation of inability to perform any adult social function that there is no other descriptor needed by the public.”[34] In other words, disabled people are too often conceived of as wholly impaired—having no abilities or social functions—in order to differentiate them from “the abled.” The erasure of their numerous positive traits occurs as a result of stereotyping, and the categorization of people as a whole on the basis of one exclusive trait.

Critics of dominant constructions of disability emphasize that everyone is in some way impaired or physically different, and that definitions of what constitute impairment and disability are socially constructed.[35] However, determinations of identity based upon genetic makeup contribute to the fear that the focus on genetic and biological underpinnings of traits, behaviour and disorders will lead to the fallacy of reductionism—describing phenomena in overly simplistic terms and neglecting complex interactions of such genes with other facets of human biology, psychology and society.[36] Since many clinicians and bioethicists assume that health status is primarily responsible for the “reduced life chances of people with disability,” genetic information may further downplay the role of *societal factors* upon peoples’ lives.[37]

Genetic information purports to tell us what someone is “really like,” thereby relieving us of the need to look for signs, symptoms or other overt characteristics. Human difference, when labelled genetically, opens the door to the most profound forms of stigmatization.[38]

Prior to the advent of genetic testing, renderings of the normal healthy state of the body looked not only at the body as a whole, but at the relative condition of individual organs or tissues within the body in order to determine one’s state of health.[39] Presently, however, “disease” is predominantly being linked to the presence of genetic “flaws.” When genetic mutations are

implicated in the development of our knowledge of disease, our understanding of health risks become effectively geneticized.[40] Genetic knowledge incorporates and builds upon the concept of normalcy —it alters our understanding of what normal bodies are. Difference and abnormality are isolated by genetics in terms of “genetic potential,” rather than in relation to the *ability of an individual to function in society*. By narrowing the scope of inquiry into the normalcy of bodies to the composition of one’s genes, information obtained through genetic testing locates both the normal and the abnormal in terms of genetic “essences.” This directly affects the way we conceptualize and value those with disabilities. It predicates a movement away from (potentially) broadly based inquiries into what disabled people need to be full participants in society, and leads to the framing of questions about disability in terms of how disabled peoples’ “abnormalities” can be corrected and improved upon. Indeed, it also raises questions about whether disabled people should exist at all.

Could genetic information allow us to rethink the way we have narrowly constructed and stigmatized the category of disability? Could it allow us to more easily picture the ways that we are united by our similarities as well as our many differences? Genetic testing offers us the potential to demonstrate that we are all in some way “impaired” by highlighting the magnitude of human genetic variation, and by demonstrating that everyone has genetic “abnormalities.” This appears to be akin to the historical construction of the human body as less than ideal, and fraught with imperfection. Seemingly, it is also in line with the position of the disability movement that it is desirable to see everyone as in some way impaired in order to ensure the inclusion of those with disabilities as equal members of society. Unfortunately, a negative response to these questions is inevitable precisely because the new genetic project is premised upon the *identification and improvement of deleterious genes*. The objectives of the Human Genome Project are clearly framed as “the use of genetic information... to ensure that... each individual has at least a modicum of normal genes.”[41] This maintains and reinforces the division between the normal and the abnormal, and unequivocally retains the category of disability as premised upon undesirable *genetic differences*. Without the presence of a socially relevant “difference” to be eradicated or enhanced by genetic science and technology, the new genetic project has no relevance and, importantly, it has no viable market. Thus, genetics reinforce the understanding of disability as impairment at the same time as it expands the class of disability to include a wider variety of genetically based “impairments” in need of repair or improvement. Without coincidence, the number of individuals whose genes are believed to be in need of repair or improvement also multiplies.

Divergent opinions about what genetic technology and information ought to be utilized to accomplish rest on different constructions of normalcy, and different ideas about what should be done upon identification of a “genetic” norm. Proponents of genetics and the exploration of the human genome believe that applying the scientific knowledge of heredity will improve human lives. They believe that genetic information should be used either to bring people up to the norm, or to improve upon the “average” characteristics within the human race. “According to the proponents of the new genetics, the pursuit of progress through the application of scientific knowledge is based on a universalistic, nonexclusionary conception of the value of human lives, rather than on a pernicious view that what is valuable is the assumed distinctive characteristics of some particular race or nation or social class.”[42] With this as its basis, the debate over the new genetics becomes centred around questions about *which conception* of normalcy should guide our actions. Should genetics be used to bring everyone into line with the average, or should it be used to enhance and improve upon those averages?

There is no consensus, even within the disability community, about whether certain prenatal genetic tests are accept-able and desirable, while others are not. For example, wholesale restrictions on prenatal testing for genetic disability are not sought by members of this community, as many believe that the use of genetic tests to highlight the presence of a fatal condition such as Tay Sachs disease *is* morally justified.[43] Agreement can only be reached

around where and how the power to make such decisions should lie—it should be a genuine choice made by informed individual parents, which is neither constrained by healthcare funding, nor based upon narrowly defined determinations of the severity of particular conditions.[44] Although not easily reached, this consensus acknowledges that genetic technologies do have the potential to be beneficial to everyone—to the extent that they provide us with the ability to expand reproductive choices, extend lives and provide new treatments for various conditions.[45]

However, at the same time we must understand and acknowledge that the geneticization inherent in genetic testing perpetuates and reinforces entrenched ideas about disability as an abnormal, undesirable, individual medical concern. While genetic screening and selective abortion appear to address much lauded concerns about the costs of treatment, and the availability of services for people with disabilities, it is a discriminatory practice which places a price on human life.[46] Further, it obscures the extent to which genetics further legitimates the political and social control of human difference.

The practice of termination of fetuses upon detection of “abnormality” or disability as a result of prenatal testing and diagnosis is precisely that which is feared by those who are alarmed about the potential directions the new genetics take. Catherine Frazee forcefully inquires:

For those of us with “undesirable” genetic characteristics that could have been detected before birth, the implications of such informed decision-making are genocidal. Had our parents or their physician advisors been “better informed,” how many more of us would have been denied the possibility to experience life, think our own thoughts or form our own opinions and value systems?[47]

Critics of genetics reject the “universalism” of the new genetics as exclusionary and regressive. “What differentiates prenatal testing followed by abortion from other forms of disability prevention and medical treatment is that prenatal testing followed by abortion is intended not to prevent the disability or illness of a born or future human being but to prevent the birth of a human being who will have one of these undesired characteristics.”[48] Genetic articulations of normalcy and disability attempt to devalue *disabilities* them-selves, not the people with the disabilities. Arguments in favour of the value of prenatal testing rely upon the notion that fetuses are not persons, in order to rationalize the position that no person—disabled or otherwise—has a right to be born.[49] However, the practice of selective abortion in the context of a society in which impairment is conflated with identity, and in which stigmatization and subordination of the disabled is entrenched within the medical and political paradigm of normalcy, *does* profoundly devalue the disabled. It sends a very clear message about the abnormality and undesirability of disabled persons.

The construction of normalcy that promotes the betterment of the human species is reflected in the notion of genetic enhancement. This practice also invokes genetics to improve upon present norms, characteristics and persons—although it has the potential to embark upon new levels of intervention. Much debate is occurring over the morality and desirability of such practices, predominantly since genetic enhancement is not based upon what is presently considered “medical need.” It is based on other, often-unspecified criteria. Enhancement is non-therapeutic, in other words, it does not relate to the eradication or treatment of what we presently construe as illness, disease or disability. Its objectives are most likely economic, social, cultural or ethnic in nature. Thus, to many, genetic enhancement does not represent a “real medical problem.” However, in view of the ever-shifting boundaries of these categories in light of new genetic information and technologies, again new questions beg to be answered. Which types of enhancement should be permitted? Who would have access to the procedures? Again these questions are firmly entrenched within the phenomenon of geneticization, and they obscure the impacts of this paradigm upon the disabled. In order to render this debate relevant to the interests of the disabled, we must continue to interrogate the effects of genetically based constructions of normalcy. To do so, we must ask: “[i]f the ability to make a selection exists, what will be the

effect on those who do not meet the standards of societal norms?”[50] Proponents of the new genetics offer a response framed in terms of normal species functioning, which to them appears relatively unproblematic.

It is conceivable that genetic enhancements of normal human functions, if sufficiently valuable and widespread, might lead us to revise upward our conception of normal species functioning, with the result that where we draw the line between health and disease, and hence between enhancement and treatment, would correspondingly change. If this occurred, we might come to view a certain intervention as being required by justice even though previously we had regarded it as an optional enhancement that individuals might be allowed to seek, but to which none was entitled... If such enhancements became wide-spread, we might come to regard a person who lacked them as suffering from an adverse departure from normal functioning.[51]

However, if this were to occur, the disabled would be increasingly devalued and labelled deviant as they would be pushed further and further below “the norm”—along with many more of us whose “substandard” genes would land us within the category.

There is no moral calculus that automatically yields advice as to where the limits to our uses of the new genetics should be drawn, nor is there a rational way of constructing such limits. It is a political, public policy decision. It is imperative, however, that we acknowledge that regardless of where we “draw the line” in terms of acceptable genetic tests and interventions, doing so on the basis of normalcy will deleteriously affect the lives of the disabled. Genetics is an *a priori* exclusion of difference and disability. It begins with assumptions about the positive value of species normal functioning, which create and mark disability/impairment as abnormal, and in need of elimination, correction or enhancement. Yet, genetic testing and diagnosis are socially and politically desirable in that they are understood to resolve the dilemma surrounding disability and equality. By locating abnormality within our genes, theoretically, the disabled are not disenfranchised. Arguments that we, as individuals, are only responsible for the exertion of a preference (of the genetic type) for the lives of those we hold dear—not to everyone—become rational and morally justified.[52] The “abnormal” gene becomes the focus of social action by “responsible” individuals providing for themselves and exercising their full citizenship rights, without denying the disabled theirs. The abnormal is no longer located at the fringes of society; genetics squarely situate abnormality within the individual body.

“Normalcy” provides us the lens through which we can view and reject the exclusion of the disabled perpetuated by genetics. It forces us to acknowledge that when, and if, we decide upon the acceptable and permissible limits of the new genetics, we are also acting to severely devalue and diminish human differences. To include the interests and rights of the disabled within our social and political agenda we need to include within our policy discussions consideration of other, more broad directions or solutions which are not premised upon the stigmatization, subordination and eradication of difference. “Preventative methods that focus on making the lives of people better, rather than attempting to create better people, do not pose risks to people with disabilities.”[53] It is fundamental to understand that people living with “disabilities” are deserving of the respect due equally to all persons. Recognizing the non-neutrality of a trait and the “ab-normality” of a person’s needs is necessary for expressing the commitment to moral equality and equal opportunity.[54] Genetic testing and intervention obscure the idea that the privileging of the normal and the “genetic norm” is an exercise we might abandon altogether in order to reconceptualize and revalue disability, difference and equality.

Note

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1. I. Hacking, *The Taming of Chance* (Cambridge: Cambridge University Press, 1990), p. 163.

2. *Ibid.*, p. 160.

- [3.](#) *Ibid.*, p. 163.
- [4.](#) International League of Societies for Persons with Mental Handicap, *Just Technology? From Principles to Practice in Bio-ethical Issues* (North York, Ontario: The Roeher Institute, 1994), p. 10.
- [5.](#) J. Fitzgerald, "Geneticizing Disability: The Human Genome Project and the Commodification of Self," *Issues in Law and Medicine*, Vol. 14, no. 2 (1998), pp. 147-163, at p. 152.
- [6.](#) L.J. Davis, *Enforcing Normalcy: disability, deafness and the body* (New York: Verso, 1995), pp. 24-25.
- [7.](#) Hacking, *supra note 1*, p. x.
- [8.](#) E. Ettorre, "Reproductive Genetics, Gender and the Body: 'Please Doctor, may I have a Normal Baby?'" *Sociology*, Vol. 34, no. 3 (2000), pp. 403-420, at p. 412.
- [9.](#) *Ibid.*
- [10.](#) Hacking, *supra note 1*, p. xi.
- [11.](#) Davis, *supra note 6*, p. 26.
- [12.](#) Davis, *supra note 6*, p. 29.
- [13.](#) Hacking, *supra note 1*, p. xi.
- [14.](#) Davis, *supra note 6*, p. 30.
- [15.](#) *Ibid.* The irony of the desire to normalize a population arising from the development of statistical determinations of the "average" is that the, "rule of statistics is that all phenomena will always conform to a bell curve."
- [16.](#) *Ibid.*, p. 31.
- [17.](#) *Ibid.*, p. 33.
- [18.](#) *Ibid.*
- [19.](#) *Ibid.*, p. 35.
- [20.](#) N. Daniels, *Just Health Care* (Cambridge: Cambridge University Press, 1985), p. 42.
- [21.](#) *Ibid.*, p. 28 [*emphasis added*].
- [22.](#) A. Asch, "Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy," *American Journal of Public Health*, Vol. 89, no. 11(1999), pp. 1649-1657, at p. 1651.
- [23.](#) *Ibid.*, p. 1650.
- [24.](#) A. Buchanan, "Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion," *Social Philosophy and Policy*, Vol. 13, no. 2 (1996), pp. 18-46, at p. 25.
- [25.](#) S. Tremain, *Risk and Disability in Genetic Counselling Discourse: A Critical Review* (The Roeher Institute, *unpublished manuscript*, 2001), p. 29.
- [26.](#) Buchanan, *supra note 24*, p. 19 [*emphasis in original*].
- [27.](#) A. Asch and G. Geller, "Feminism, Bioethics and Genetics," in S.M. Wolf, (eds.), *Feminism & Bioethics: Beyond Reproduction* (New York and Oxford: Oxford University Press, 1996), pp. 318-350, at p. 323 [*emphasis added*].
- [28.](#) A. Buchanan, D.W. Brock, N. Daniels and D. Wilker, *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2000), at p. 24 [*emphasis added*].
- [29.](#) *Ibid.*, p. 270.
- [30.](#) Asch, *supra note 22*, p. 1650.
- [31.](#) J. D. Watson, "President's essay: genes and politics," (Annual Report Cold Springs Harbor, 1996) in Asch, *supra note 22*, pp. 1651-52.
- [32.](#) Tremain, *supra note 25*, p. 29.
- [33.](#) T. Shakespeare, "What is a Disabled Person?" in M. Jones and L.A. Basser Marks, (eds.), *Disability, Diversability and Legal Change* (Great Britain: Kluwer Law International, 1999), pp. 35-47, at p. 26.
- [34.](#) Davis, *supra note 6*, p. 9.
- [35.](#) T. Shakespeare, "'Losing the plot'? Medical and activist discourses of contemporary genetics and disability," *Sociology of Health & Illness*, Vol. 21, no. 5 (1999), pp. 669-688, at p. 29.
- [36.](#) Asch and Geller, *supra note 27*, p. 327.

- [37.](#) E. Parens and A. Asch, “The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations,” Special Supplement, *Hastings Center Report* 29, no. 5 (1999), p. S8 [*emphasis added*].
- [38.](#) J. Bickenbach, “The Perils of Human Genetics,” 1 *Ethics and Intell. Disability* 2 (1996) in Fitzgerald, *supra note 5*, p. 153.
- [39.](#) Hacking, *supra note 1*, p. 166.
- [40.](#) A. Lippman, “Prenatal testing and screening: Constructing needs and reinforcing inequities,” *American Journal of Law and Medicine*, Vol. 17, no. 1,2 (1991), pp. 15-50.
- [41.](#) Asch and Geller, *supra note 27*, p. 323.
- [42.](#) Buchanan, *supra note 24*, p. 19.
- [43.](#) Parens and Asch, *supra note 37*, p. S16.
- [44.](#) *Ibid.*, pp. S16-S19.
- [45.](#) *Just Technology?* *supra note 4*, p. 1.
- [46.](#) *Ibid.*, p. 21.
- [47.](#) C. Frazee, “Obscuring Disability: The Pursuit of ‘Quality’ in the CBS,” in F. Miller, L. Weir, R. Mykitiuk, P. Lee, S. Sherwin and S. Tudiver, (eds.), *The Gender of Genetic Futures: The Canadian Biotechnology Strategy, Women and Health* (Toronto: NNEWH Working Paper Series, September 2000), pp. 191-198, at p. 194.
- [48.](#) Asch, *supra note 22*, p. 1651.
- [49.](#) Buchanan, *supra note 24*, p. 32.
- [50.](#) *Just Technology*, *supra note 4*, p. 12.
- [51.](#) Buchanan, *et al*, *supra note 28*, pp. 98-99.
- [52.](#) *Ibid.*, p. 26.
- [53.](#) *Just Technology*, *supra note 4*, p. 8.
- [54.](#) Parens and Asch, *supra note 37*, p. S15.
-