

# Norm Change in Genetic Services

How the Discourse of Choice Replaced  
the Discourse of Prevention

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## Mudanças de norma em serviços genéticos

Como o discurso da escolha substituiu o discurso da prevenção

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**RESUMO** Nos anos 1960 e 1970 era geralmente suposto que as escolhas reprodutivas tinham consequências e, assim, eram uma questão de interesse social. O comportamento reprodutivo socialmente responsável, por sua vez, era presumido como capaz de minimizar o risco de transmitir doenças genéticas graves. Com o tempo, tal visão veio a ser cada vez mais rotulada de “eugenia”, um termo que adquiriria na maior parte do mundo conotações fortemente negativas. A partir dos anos 1990, este velho ponto de vista tornou-se amplamente substituído no Ocidente pelo princípio de que a reprodução é uma questão privada e que não haveria certo ou errado nas decisões reprodutivas. O principal propósito deste artigo é explicar e interpretar esta transformação, que foi um produto principalmente dos anos 1980. Baseando-se na teoria das normas sociais, na qual supõe-se que as normas são sempre contestáveis em alguma medida, discute-se como aqueles com um interesse nas mudanças das atitudes predominantes são capazes de alcançar tal sucesso aparente rapidamente.

**PALAVRAS CHAVE** normas, diagnóstico pré-natal, eugenia

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**ABSTRACT** In the 1960s and '70s, it was generally assumed that reproductive choices have social consequences and thus are a matter of social concern. Socially-responsible reproductive behavior, in turn, was assumed to entail minimizing the risk of transmitting grave genetic diseases. Over time, such a view came increasingly to be labelled "eugenics," a term that would in much of the world acquire strongly negative connotations. By the 1990s, the old view had been largely replaced in the West by the tenet that procreation is a private matter, and that there are no right or wrong reproductive decisions. The primary aim of this essay is to explain and interpret this transformation, which was largely a product of the 1980s. Drawing on social-norms theory, which assumes that norms are always to some degree contested, it asks how those with an interest in changing prevailing attitudes were able to achieve such apparent rapid success.

**KEYWORDS** norms, prenatal diagnosis, eugenics

## **SOCIAL NORMS AND THEIR DYNAMIC**

In his Coase Lecture of 1995, the legal and social theorist Cass Sunstein (1995; 1997) analyzed the life-cycle of norms and in particular a phenomenon he termed "norm cascades." Sunstein noted that normative change sometimes occurs with striking rapidity. Thus, there may seem to be a consensus on some standard of behavior, for example that homosexuality should be a criminal offense or that interracial marriage should be discouraged. For most people, these precepts will appear to be sheer common sense. Yet such apparently taken-for-granted norms are sometimes abandoned with surprising speed. Sunstein asked: How and why does this happen?

That question has also been posed by a host of other scholars, including both philosophers and empirically-minded social scientists, primarily economists and social psychologists. Indeed, the authors of a recent working paper on social norms and their measurement comment on the current "bewildering array of social norms models and their terminologies." Fortunately, as they also note, the models tend to

agree on a few key tenets, in particular, that social norms are maintained by shared beliefs about what others do and think should be done and by the expectation that publicly going against the grain (either in deed or word) will be costly, eliciting overt or covert social disapproval or even stronger sanctions (Mackie; Moneti, 2014).

Theorists also assume that not everyone within the relevant reference group will share the prevailing perspective; that norms are almost always to a greater-or-lesser degree contested.<sup>1</sup> Agents who hold contrary views about what constitutes appropriate or desirable behavior in their community or the larger society may actively strive to change standards. In past 50 years, examples of these “norm entrepreneurs” would be civil rights activists, animal-rights activists, and environmentalists; in respect specifically to the domain of genetic services, they would also include feminists, bioethicists, and religious, patient-advocacy, and disability-rights activists.<sup>2</sup> These agents can exploit the fact that what appears to be an entrenched consensus may in reality be quite shallow. Thus, some individuals’ private judgments may diverge from those they feel comfortable articulating in public since to do so would brand them as deviant. Occasionally, they will even be mistaken in their assumptions about what most others believe; in situations where it is difficult to evaluate the content and prevalence of others’ beliefs, their judgments may in fact be much less deviant than they realize (a situation known as “pluralistic ignorance”).

When for whatever reason allegiances are weak, even small jolts — from new information, technology, law, or elsewhere — can make a large difference, in some cases enabling those with an interest in norm change to achieve rapid success. When enough people are convinced to either change their minds or reveal their true beliefs, the cost (real or presumed) of expressing what had been an aberrant view is lowered.

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1 Other important theorists of norm dynamics include ALEXANDER, 2007; APPIAH, 2010; BICCHIERI, 2006; BICCHIERI; MULDOON, 2011; BICCHIERI; MERCIER, 2014; CIALDINI, 2011; ELSTER, 2015; SKYRMS, 2004.

2 On women’s equality activists as norm entrepreneurs see DEMPSEY; MEIER, 2009.

If a tipping point is reached, the result is a norm cascade, where it becomes the older view that now evokes social disapproval. A recent example from the US would be opinion on gay marriage, which flipped in about a decade. In the end, the new norms may become so widely endorsed that they achieve the same taken-for-granted quality as those they replaced. And once internalized, they become essentially invisible because they are no longer challenged. This trajectory appears to have been the one followed by norms related to reproductive behavior, where widely-accepted views about what was appropriate in the 1960s and '70s became nearly unthinkable (or at least unspeakable) in the US, UK, France, Germany, and most other highly-industrialized Western countries by the 1990s. We begin the analysis with a brief mapping of the landscape of genetic services — genetic counseling, prenatal diagnosis, carrier testing, and newborn screening — in the early period, when the injunction to reproduce responsibly was widely endorsed both by service providers and their patients/clients.

## **GENETIC COUNSELING AND PRENATAL DIAGNOSIS, 1965-1980**

A half-century ago, reproductive genetic services primarily consisted of genetic counseling, or as it was then often called, genetic consultation or genetic advice, a practice that had slowly expanded since its origins in the 1930s. Individuals sought counseling for a plethora of reasons. According to Sheldon Reed's *Counseling in Medical Genetics* (1963, p.156), the single largest group seeking help at the University of Minnesota's Dight Institute, which he directed, was prospective adoptive parents anxious to know whether a child of mixed racial ancestry could pass for white (and if they could, and married into the white community, what the color and facial features of the offspring would be.) Another common concern was the genetic risk of marrying a cousin. But in the US and presumably elsewhere, most clients were prompted to seek help by the presence of disease that had already appeared in their families.

Sometimes the goal was a diagnosis for an affected child, but it was almost always (or also) knowledge of potential reproductive risks. In respect to those risks, counselors were generally limited to providing statistical probabilities, and when the probability was substantial, the only means to act on the knowledge was to refrain from reproduction or further reproduction. Demographically, counseling was skewed toward the well-educated and financially secure. Advice was often — though not always — highly directive, at least when clinicians were confident that the condition manifested in children, its causation was truly genetic, and that they need not be concerned about incomplete penetrance and variable expressivity.<sup>3</sup> But even non-directive practice was usually based on providers' assumptions that prospective parents who availed themselves of counseling services were unusually well-educated and responsible people who would make the right decision and that, in any case, they generally possessed good (heritable) mental and moral traits, which they would transmit to offspring (Paul, 1997; Comfort, 2012; Stern, 2012).<sup>4</sup>

In respect to both its size and scope, genetic services soon markedly expanded. In 1963, there were 28 genetics centers in North America. Within a decade, there were 387 in the US alone (Cottebrune, 2013, p.195). And whereas the only reproductive genetic service on offer had once been genetic counseling, the 1970s witnessed the development of both prenatal diagnosis (PND) and carrier testing. The rapid diffusion of PND, initially in the form of amniocentesis, reflected a convergence of technoscientific and social developments. Although amnio was not a new procedure, its value greatly increased with scientific and technical advances of the 1960s that enabled the culturing of fetal cells collected

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3 On counseling in situations where the genetics was less straightforward see Bosk, 1992; Palladino, 2001; 2002.

4 Writing of Sweden, BJORKMAN, 2015, p.492, p.504, notes the concern of Nils von Hofsten, heredity expert on the Swedish Medical Board, and his colleagues, that individuals who suffered from “heredophobia” (fear of producing genetically defective offspring) “often belonged to the segment of good parental material that should be encouraged to reproduce.”

from the amniotic fluid and later the biochemical analysis of amniotic fetal cell cultures to detect inherited metabolic disorders. Advances in human cytogenetics also made it possible to diagnose some congenital malformations such as Down Syndrome and other autosomal trisomies as well as sex chromosome anomalies, and by the late 70s, alphafeto-protein (AFP), a marker for Down Syndrome, could be measured in maternal blood.<sup>5</sup> Another factor in expanding PND was progress in obstetrical ultrasound that allowed doctors to visualize the trajectory of the needle, making amnio much safer.<sup>6</sup> In the mid-1970s, studies in the US, the UK, and Canada confirmed that it had become a low-risk procedure, increasing its acceptability. In short, PND became increasingly accurate, easier, and safe, while its scope expanded. However, these technical and scientific developments would have counted for little in the absence of the decriminalization of abortion in a majority of Western countries including the UK in 1968, the US in 1973, and France in 1975. Once it was possible to terminate a pregnancy on the basis of test results, the use of PND exploded. By the end of the 1970s, the procedure in many countries had become routine for women over age 35.

Initially, state support for prenatal diagnostic services was typically justified as cost-saving on the grounds that use of these services would prevent the births of children with expensive disorders. In the 1970s, when such services were generally first established, and continuing well into the 1980s, it was common for geneticists as well as health economists and policy analysts to stress the financial burden to society of caring for individuals with chromosomal abnormalities such as Down Syndrome and the value of reducing that burden through expanded preventive genetic services. Such arguments often invoked cost-benefit analyses (Paul,

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5 A “triple test” that detects elevated levels of hCG, and Estriol as well as AFP and thus also identifies risk for neural tube defects and trisomy 18 (Edwards Syndrome) later increasingly replaced the single maternal serum AFP test for Down Syndrome. For a detailed account of scientific and technological changes in the domain of prenatal diagnosis see LOWY, 2014a; 2014b, and her forthcoming book, *Tangled Diagnoses: Prenatal Testing, Women, and Risk*.

6 By 1974, most US hospitals that did amnio also used ultrasound. COWAN, 2008, p.99.

1998).<sup>7</sup> Today, the use of cost-benefit reasoning, in which the abortion of fetuses with disabling conditions counts as a benefit of reproductive genetic services, has fallen out of favour, with critics condemning such reasoning as “eugenics.”<sup>8</sup> But until the mid-1980s, the explicit use of such cost considerations raised few hackles, consistent as it was with the prevailing norm that prospective parents had a moral obligation to do what they could to avoid giving birth to children who would be cognitively or physically impaired. That norm is nicely illustrated by the following comment by Aubrey Milunsky and Philip Reilly (1975, p.74-75), editors of a highly influential series of books on legal and ethical issues in genetic services: “Traditionally, society has not taken a benign view of persons likely to have defective offspring. Every state forbids some degree of consanguineous marriage. Compulsory sterilization laws applying to institutionalized retardates may be found in the statutory codes of more than twenty states. Furthermore, these laws have withstood constitutional challenge.” Through at least the 1970s, the ethical and legal literature relating to genetics was rife with similar comments (Paul, 2002).

Of course there were dissenters, especially among those disturbed by the legalization of abortion. In the US, a particularly influential secular critic was Leon Kass, a non-religious Jew and important figure in the nascent field of bioethics. Although Kass had moral qualms about abortion, he was not opposed to its use under all conditions. He did object to selective abortion, believing that it undermined “the belief in the radical moral equality of all human beings,” and he asked whether, having finally managed to remove much of the stigma associated with genetic disease and to develop programs of care and support for its victims, “the development of amniocentesis and prenatal diagnosis may represent a

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7 The positive cost-benefit ratio was also the primary reason why age 35 became the cut-off for amniocentesis. RESTA, 2002.

8 However, “eugenics” retained favorable connotations and the goal of genetics services remained explicitly preventive, in China, India, Thailand and other Asian and South Asian countries, in socialist or recently-socialist countries such as Russia, Hungary, the Czech Republic, Vietnam, and Cuba, and in several South American countries including Brazil, Peru, and Venezuela. WERTZ, 1997a, p.333-336; WERTZ; FLETCHER, 2004, p.44-50; GAMMELTOFT, 2007.

backlash against these same humanitarian and egalitarian tendencies in the practice of medicine, which by helping to sustain to the age of reproduction persons with genetic disease has itself contributed to the increasing incidence of genetic disease, and with it, to increased pressures for genetic screening, genetic counseling, and genetic abortion.” He also suggested that selective abortion would affect attitudes towards those with the disease, “as one unfit to be alive ... a person who need not have been, and who would not have been, if only someone had gotten to him in time” (Kass, 1976, p.315-317).

But most of those who wished to change the prevailing norm were orthodox Catholics opposed to abortion *per se*. In 1969, French geneticist Jérôme Lejeune was awarded the prestigious William Allan Award of the American Society of Human Genetics for the discovery that Down Syndrome resulted from an extra copy of chromosome 21.<sup>9</sup> To the chagrin of his listeners, Lejeune, an ardent Catholic, used the acceptance speech to condemn PND and abortion. He imagined that a new and more appropriate title and agenda for the US National Institutes of Health, which funded much of the work on PND, would read: “Elements of the Statutes of a New Facility for Research and Applied Eugenics. Article I. Considering the disputed issue of mankind’s betterment, noting the burden imposed upon society by genic and chromosomal diseases, and recognizing The limitation of the available solutions, a special Institution for Research and Applied Eugenics is created: “THE NATIONAL INSTITUTE OF DEATH”” (Lejeune, 1970). Lejeune’s host, Charles Epstein (2002), who had just founded the PND program in California, later described his and his colleagues’ shock at the speech.<sup>10</sup> But perhaps the

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9 Controversy has recently erupted over the relative contributions of and credit accorded to Lejeune and Marthe Gautier to the discovery. GAUTIER; HARPER, 2009; PAIN, 2014.

10 Although EPSTEIN, 2002, p.311, never opposed abortion, he eventually came to share some of Lejeune’s concerns, noting in his own Allan address that: “As much as we talk about neutrality and non-directiveness in genetic counseling, the message that these programs convey is that it is really not all right to give birth to a child with serious abnormalities.” STERN, 2012, p.137, describes the correspondence between Lejeune and Melissa Richter, who founded the first US genetic counseling program at Sarah Lawrence College in 1969.



most notable aspect of the intentionally-provocative speech is how little attention it attracted at the time from journalists or other commentators. In 1969, prior to the US Supreme Court's decision in *Roe v. Wade* decriminalizing abortion, there was little political mobilization around that issue and hence few individuals or groups primed to seize on and publicize Lejeune's comments.

## CARRIER SCREENING

Even in the 1970s, PND was not the only reproductive genetic service on offer. By 1975, more than 40 recessively-inherited autosomal disorders could be identified by biochemical methods in healthy carriers. In general, these methods were not useful for mass screening, but in the US, there were large and well-publicized programs of ethnically-targeted screening for both Tay-Sachs disease (TSD; formerly infantile amaurotic family idiocy), and sickle-cell disease (SCD). TSD is a recessive disorder resulting from a deficiency of the hexosaminidase A (hex A) enzyme. Characterized by rapid and progressive destruction of nerve cells in the brain and spinal cord, children with TSD generally die by the age of 4. There is no treatment. The gruesome and invariably fatal nature of the disease, along with commonly-shared assumptions about reproductive responsibility — accepted even by those who considered themselves and were considered by others critics of eugenics — explains why anthropologist Ashley Montagu (1959, p.305-306) could write that, “there can be no question that infantile amaurotic family idiocy is a disorder that no one has a right to visit upon a small infant. Persons carrying this gene, if they marry, should never have children, and should, if they desire children, adopt them.”<sup>11</sup>

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11 Theodosius Dobzhansky, like Montagu considered a critic of eugenics, remarked that persons who carry serious genetic defects should be persuaded not to reproduce, and if persuasion should fail, “their segregation or sterilization is justified. We need not accept a *Brave New World* to introduce this much of eugenics” (DOBZHANSKY, 1962, p.333). The Swedish geneticist Gunnar Dahlberg, another passionate critic of eugenics also assumed that sterilization was justified to prevent mentally-disabled individuals from becoming parents. BJORKMAN, 2015, p.494.

A National Tay-Sachs and Allied Diseases (NTSAD) program to screen for the disease began in 1972 and by 1975 more than 100,000 American Jews had been tested (Wailoo; Pemberton, 2006, p.37). Screening is typically a prelude to prenatal diagnosis and selective abortion. But abortion is not acceptable to Orthodox Jews, who sometimes employ preimplantation genetic diagnosis (since embryos have a different status than fetuses in this community) or, beginning in the early 1980s, premarital carrier tests, with results communicated to matchmakers or other third parties and not to the individuals themselves.

The best-known example of the latter is the *Dor Yeshorim* program, which began in New York but soon expanded to Israel and eventually many other countries. The combined effect of these and other programs, such as open testing at a clinic or hospital where clients are told the results directly, have essentially eradicated TSD in the American and Israeli Jewish populations, although the matchmaking programs have sometimes been criticized as a form of eugenics (Raz, 2010).

A year before establishment of the NTSAD program, sickle-cell screening had been introduced by the Black Panthers, a revolutionary black-liberation group founded in 1966, which began testing African-Americans at community gatherings, in health clinics, homes, schools, parks, and at rallies and other public events. At the same time, the Panthers also established the People's Sickle Cell Anemia Research Foundation (PSCARF), with the aim of finding a cure for the disease (Nelson, 2011, p.116, p.122). Responding to political unrest in black community, in 1972 the US Congress passed the National Sickle Cell Anemia Control Act, which sharply increased funding for research and prevention. Testing of African-Americans was also mandated in 12 states and the District of Columbia — despite the fact that the portable screening test then in use did not distinguish the disease from the relatively harmless trait (i.e., the affected from carriers), and that there was no cure for the disease and no practical means for diagnosing it prenatally.<sup>12</sup>

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12 The situation in the US contrasts markedly with that in France, where ethnicity is not generally considered a relevant variable for medicine, including genetic testing and screening.

The original hope in respect both to TSD and sickle-cell anemia had been that an effective treatment would emerge from research. But in both cases the hopes were disappointed, and as with PND, the point of screening became prevention of births. As physician Robert Scott, whose influential critiques of the lack of attention to sickle cell disease prompted the Panthers' campaign, expressed the point:

Since the disease is incurable and no effective management is available, prevention is the only practical alternative at present. Prevention requires identification of heterozygotes, which can be readily done by sickle-cell preparation or hemoglobin electrophoresis. These tests should be offered before marriageable age. If such tests were widely available, young Negroes would have, for the first time, the opportunity to make informed decisions about childbearing. (Scott, 1970a, p.164).

A prominent member of the PSCARF advisory board was American biochemist and political activist Linus Pauling, who had identified the molecular basis of sickle-cell anemia in 1949. Among Pauling's many causes — which included civil rights and nuclear disarmament — was the prevention of genetic deterioration, which he viewed as an imminent threat arising both from increased exposure to ionizing radiation and advances in modern medicine. In 1968, Pauling infamously proposed that all young people should have tattooed on their forehead symbols for any seriously defective recessive genes, such as those producing sickle-cell anemia and PKU.<sup>13</sup> He also thought that “legislation along this line, compulsory testing for defective genes before marriage, and some form of public or semi-public display of this possession, should be adopted”

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LOWY; GAUDILLIÈRE, 2008, relate the French aversion to ethnicity-based genetic testing to a “universalist conception of citizenship,” which discourages a focus on ethnic differences.

13 PAULING, 1968, p.269, expressed confidence that, if this were done, carriers for the same defective gene “would recognize the situation at first sight, and would refrain from falling in love with one another.” He reiterated this proposal in a speech at the 1968 dedication of the new Mt. Sinai School of Medicine. PAUL; BROSCO, 2013, p.68, p.268.

(1968, p.9).<sup>14</sup> Although Pauling was concerned that, in the long-term, an effect would be a slight increase in the future incidence of disease genes, he thought that result could be countered through an educational process aimed at convincing carriers “married to normals” to have fewer than the average number of children (Pauling, 1968, p.269-270).

In his views on genetic disease, as on many topics, Pauling was certainly an outlier. But it is notable that, at the time, his proposal occasioned little comment. Sentiment in the black community would later turn fiercely against sickle-cell screening programs, with black activists equating such programs with genocide and associating them with coercive sterilization and unethical medical experimentation (Markel, 1998; Randall, 2008). That turnaround is largely explained by the persistent confusion between those affected and carriers, with resulting discrimination in insurance and employment against individuals with the (usually benign) sickle-cell trait. But as with the use of cost-benefit analysis and PND, it also reflects the different ethos of the time. Ideas about reproductive responsibility that would have seemed commonsensical in the 1960s and ‘70s were by the 1980s viewed as eugenics, now assumed to be unreservedly bad.

## NEWBORN SCREENING

A very different kind of genetics program also came into being in the 1960s: the screening of newborns for the autosomal recessive disease phenylketonuria. PKU is neither common nor contagious. Yet routine screening of newborns as a public health program began in early 1960s, and by 1965, 32 US states had enacted screening laws, all but five making the test compulsory. By the decade’s end, screening for PKU had become routine in most US states and Canadian provinces, the Antipodes, the UK, France, and Germany, and by the mid-1970s, it was near-universal in Central and Northern Europe and had even extended to several poor countries.

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<sup>14</sup> Pauling’s essay was specifically cited in the 1972 Kentucky law mandating SCD screening.

Babies born with PKU have an impaired ability to metabolize phenylalanine, an essential amino acid found in all dietary proteins. The phenylalanine ingested in food thus accumulates in the blood and body tissues, producing profound cognitive impairment and other physical and neuropsychological anomalies. Researchers hypothesized that the effects of the disease might be ameliorated if affected infants were fed a formula from which most of the offending amino acid had been removed. Although a low-phenylalanine formula became available in the 1950s, no test could reliably detect PKU in infants before they had suffered irreversible brain damage.

In 1961, such a test was invented — converging with the election of John F. Kennedy as US President. Kennedy had a sister who was institutionalized with what then was called mental retardation (MR), and he initiated a national campaign to combat MR. At the same time, parents of affected children had mobilized. Their organization, the National Association for Retarded Children, established in 1950, strongly supported the President's initiative and eventually lobbied to make screening for PKU mandatory (Paul; Brosco, 2013).

It might seem that there were few links between newborn screening for PKU and programs for prenatal and carrier screening. The personnel were certainly different, as were the institutional locations, techniques, and aims: in the case of newborn screening, the goal was treatment, not prevention of births. However, the newborn-screening and reproductive-genetics stories intersect at several points. One point of contact is that the ability to treat PKU inspired hope that other genetic diseases, such as TSD, sickle-cell anemia, and Down Syndrome, would also be amenable to treatment.<sup>15</sup> Thus, Lejeune almost certainly had PKU in

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15 In respect to TSD, the 1969 discovery of deficiency of Hex-A enzyme prompted hope that enzyme-replacement therapy would be effective. LOWY, 2014a, p.156, notes that it was after researchers had given up hope that the PKU model of biochemical correction could be extended to chromosomal anomalies that “‘genetic conditions’ became gradually synonymous with incurable ones, and the best ‘doable’ solution proposed the specialists coupled the prenatal diagnosis of such conditions with a possibility of an abortion. The prevention of genetic diseases became increasingly identified with the prevention of birth of people with such diseases.”

mind when he claimed that, if the chemical factor involved in Down Syndrome could be identified, it should be possible to avoid cognitive damage in those affected: “As far as I can see they would remain with the disease, but they could have a normal intelligence”.<sup>16</sup> Another intersection is that screening for PKU, which was rare, made it seem reasonable to screen for more common disorders such as sickle-cell. Thus Robert Scott wrote: “In any city with 30 per cent Negro population, more than twice as many children are born with sickle-cell anemia as cystic fibrosis and nearly nine times as many as phenylketonuria” (Scott 1970a, p.164; 1970b). Relatedly, it set an example of requiring that testing be mandatory. If screening for PKU had been made compulsory by law, then why not screening for sickle-cell?

Moreover, despite the fact that its aim was treatment, the establishment of newborn screening programs had implications for thinking about reproductive responsibilities and rights. First, the ability to treat PKU contributed to fears in some circles that modern medicine was dysgenic since it salvaged individuals who would otherwise not have reproduced, with a resulting increase in the incidence of the responsible genes. Thus, a historian of bioethics notes that, in the 1960s, “geneticists worried that the gene pool was becoming polluted because the early death of persons with certain genetic conditions was now preventable,” and they cited the development of antibiotics, insulin therapy for diabetes, and dietary treatment for PKU (Jonsen, 1998, p.14). Second, the successful treatment of PKU engendered the new problem of “maternal PKU.” Prior to screening and treatment, the fertility of females with severe PKU was nearly zero. In contrast, the fertility of women diagnosed as infants and placed on a low-phenylalanine diet was almost normal. When screening began, it was assumed that treatment could be discontinued after gross brain development was complete, around the age of 4 or 5. The policy of diet discontinuation meant that high levels of phenylalanine circulated in the maternal blood of once-treated

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16 ANONYMOUS. French Geneticist Explores Chemistry of Mongolism. *Toronto Daily Star* (Toronto), p.47, 12 nov. 1970.

women. Phenylalanine, which is actively transported across the placenta, is highly toxic to the fetus, and most of the children born to these women were badly damaged. Although it was in theory possible to return to the (unpalatable) diet during pregnancy, this massive challenge was infrequently met. As a result, into the 1980s the standard advice to young women who had been treated in infancy and childhood was not to get pregnant and, if they wanted to have children, to adopt. In cases of unplanned pregnancy, the most common advice was to abort.

## CAVEATS

As this brief overview of the formative period of genetic services indicates, the prevailing norm had been that prospective parents should act responsibly. In the 1960s and 70s, most genetics professionals (as well as physicians and medical ethicists) believed it wrong to knowingly risk bearing a child with a serious genetic disorder. The implication was that pregnant women at high risk should have PND and terminate if necessary, that individuals in communities where specific diseases were highly prevalent should be tested for carrier status and avoid mating with other carriers for same disorder; that women with PKU should not have biological children.

Today, in much of the world, such views would be branded “eugenics.” However, it does not follow that, in the 1960s and ‘70s, they would have been thus labeled either by those who held them or by others. One reason is that the view that people likely to transmit a serious genetic defect should not reproduce did not mark its holder as a eugenicist. Indeed, this opinion was generally shared by people who considered themselves and were considered by others to be passionate *opponents* of eugenics, most of whom also considered sterilization an appropriate response when individuals failed to act responsibly (Paul; Spencer, 2001; Paul, 2014).

Moreover, there has never been an agreed-on meaning of eugenics. Particularly relevant to the domain of genetic testing is the potential inconsistency between long and short-term goals and related inconsistent use of language. To take a concrete example: In 1964, Sheldon Reed, who invented the term “genetic counseling,” noted that:

The most important counseling problem [in relation to PKU] will be that of trying to educate affected individuals so that they will not wish to marry another affected person or a carrier. In the first instance, 100 per cent of the children would be affected and in the second case, fifty per cent. No couple has a right to produce a child with a 100 per cent chance of having PKU, and it is doubtful whether a couple has the right to take a 50 per cent chance of producing such a serious defect. (Reed, 1964, p.85).

Yet in his later history of genetic counseling, Reed (1974, p.4) called counseling “a kind of genetic social work without eugenic connotations.” What he meant was that its aim was short-run — prevention of disease in the next generation — rather than (long-term) population improvement. Indeed, he claimed that the net effect of counseling was probably dysgenic, as was every medical triumph over genetic disease “in that it increases the frequency of the unwanted gene in subsequent generations” — thus equating eugenics with long-run aims (Reed, 1974, p.84).<sup>17</sup>

When goals were immediate, the primary rationales were to avoid suffering and to save money. These aims have been weighted differently by different groups such as clinical geneticists, MA-level genetic counselors, cytologists, obstetricians, primary-care physicians, economists, health-policy analysts, and legislators, as well as by laypersons, itself a diverse group characterized by widely varying views. Thus, it matters for the analysis whose opinions are considered. We will return to this simple but often overlooked point in the conclusion.

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17 The tension between short and long-term (population improvement) goals is evident in analyses of carrier screening, which have typically relied on masking strategies. For example, programs targeting SCD, or beta Thalessemia, or TSD, and in particular the *Dor Yeshorim* program, are often characterized as “eugenic” — but they have also been considered its antithesis since they do nothing to decrease the incidence of the offending gene. Then as now, everything depends on how eugenics is defined. For this reason, I have tried to be precise: the norm at issue is that prospective parents should act responsibly, avoiding reproduction in some circumstances. I am not concerned with whether it should or should not be termed “eugenics.”



## THE TRANSFORMATION OF NORMS

British geneticist Angus Clarke, recently recalled that in the literature of the 1970s and 1980s, “there were a lot of papers about reproductive population screening which focused very much on population outcomes, cost of screening versus cost of care and things like that, which I think caused quite a bit of offence outside the medical community and made quite a few people within it uneasy.” And he went on to note that: “There was an effort to shift terminology away from cost rationales for screening through into individual and informed choice, and to some extent that has been a cosmetic operation” (Harper; Reynolds; Tansey, 2010, p.75).

In the UK, much of Western Europe, the Antipodes, and North America, this shift was prompted most importantly by the mobilization of disability-rights activists. Movement activists maintained that all life was equally worthy, and they strenuously contested the assumption that it would be better — for those with the disease as well as for their families and the larger society — if some kinds of people were not born. In the view of these activists, such assumptions rested on unwarranted beliefs about the suffering endured by individuals with disabilities and their quality of life. They claimed that most of the suffering resulted from society’s unwillingness to accommodate the needs of people with disabilities; thus rather than preventing their births through the use of prenatal diagnosis, society should provide the social supports necessary for such individuals to achieve an independent and fulfilling life. Although disability-rights activists were often on the political Left, Catholic and politically-conservative critics of abortion subscribed to essentially the same critique of genetic testing. The primary difference was (and is) that most critics who view themselves as politically progressive also support the feminist commitment to reproductive choice. These competing agendas are expressed in the argument that while terminating a pregnancy because one does not want any child is unobjectionable, while termination to avoid having a particular kind of child is not. The reach of that disability-rights argument is exemplified

by recent discussions of the Zika virus and abortion in Brazil, a country where pregnancy termination, though not uncommon, is criminalized in almost all circumstances. Deborah Diniz, a law professor who is one of the best-known campaigners for abortion rights and the leader of a group demanding that the Brazilian Supreme Court recognize women's fundamental right to terminate a pregnancy, has emphasized that "It is not the fetus's future impairments or the 'extreme negative consequences for the families affected' that moves our demand, but the urgency to protect women's rights in the epidemic" (Diniz, 2016, p.e9).<sup>18</sup> But most left-leaning critics, in Brazil and elsewhere, would nevertheless still defend a woman's right to use PND and engage in selective abortion whereas for most Catholic and conservative critics, all abortion is wrong and should be prohibited.

By the 1990s, the cost-saving rationale for genetic testing had been abandoned in the wealthier Western countries and was increasingly condemned as "eugenics." Thus, according to a report of the US National Academy of Sciences: "The goal of reducing the incidence of genetic conditions is not acceptable, since this aim is explicitly eugenic; professionals should not present any reproductive decisions as 'correct' or advantageous for a person or society" (Andrews, 1994, p.15). Reproductive genetic services were now said to aim at increasing the choices available to women. A recent set of recommendations on carrier screening issued by the European Society of Human Genetics exemplifies the shift to a choice-promoting justification: "Carrier screening aims to facilitate informed reproductive decision-making by identifying couples at risk of having an affected child." The authors also note that "in most Western countries there is consensus that the aim of reproductive screening, including carrier screening, should be to enhance reproductive autonomy and enable meaningful reproductive choices" (Henneman *et al.*, 2016,

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18 This comment was made in response to an article by TEIXEIRA *et al.*, 2016, p.603-604, that concluded: "In light of the severity of the malformations being identified ... with likely extreme negative consequences for the families affected, it would be sensible to reopen the legalization of terminations debate to offer the women choice over the decision of continuing or interrupting such pregnancies with adequate medical care and legal protection."

p.e2). Other common rationales for testing came to include providing reassurance (since most women will receive a negative result), enabling parents to prepare for the birth of an affected child, and even to facilitate treatment, despite the very limited availability of therapeutic interventions.

Why did a once taken-for-granted viewpoint virtually vanish from public discourse? How did we go from “there are right and wrong reproductive decisions, and the right one is to avoid serious genetic risk” to “there are no right or wrong reproductive decisions, you should do what’s best for you, and the job of the counselor is to help you make whatever decision is congruent with your own interests?” A brief answer is that reproductive autonomy became a dominant value when new social movements expanded the kinds of actors with an interest in changing attitudes.

As we have seen, there had always been some people who for religious or ethical reasons dissented from the prevailing norms regarding reproduction. Now they were joined by other groups which also had an interest in overturning old norms. Perhaps the most obvious and also most important were “second-wave feminists.” In the 1960s, reproductive rights moved to the center of the feminist agenda, and with it the principle that women had an absolute right to control their own bodies. The idea that there were social interests and responsibilities in reproduction was anathema to these activists. The 1960s also witnessed the emergence of bioethics as a distinct academic discipline. In the discipline’s early years, its practitioners championed the principle of respect for autonomy, generally interpreted as implying that a person “should be free to perform whatever action he wishes — even if it involves serious risk for the agent and even if others consider it to be foolish” (Beauchamp; Childress, 1979, p.56-59). A third important group was genetics professionals, such as clinical geneticists and genetic counselors, who also developed a strong commitment to reproductive autonomy. Denying that there was any correct reproductive decision, and that the goal of genetic services was to increase the choices available to women, served to dissociate genetic services from the increasingly-contentious practice

of abortion. At the same time, it also functioned to protect professionals against accusations from disability-rights activists that such services were a form of eugenics.<sup>19</sup>

## CONCLUSION

The history of genetic services would seem to map nicely onto the trajectory described by theorists of norm dynamics. There was a relatively rapid transformation, with the new norms becoming so widely endorsed that they achieved the same taken-for-granted quality as those that they replaced. The new view came to seem so obviously right that it became difficult to imagine that a diametrically opposed view had seemed commonsensical in the quite recent past. Statements that produced little if any reaction in the 1970s came to seem shocking.

However, one last caveat: the opinions available for analysis are largely those of experts; in the 1960s and '70s, most often famous geneticists and scientists in allied disciplines. Distinguished scientists dominated international conferences on ethical and policy issues in genetics, with the proceedings frequently published. But while norms were shifting in this particular reference group, so were the kinds of people interrogated for their opinions on reproductive issues. Thus, lists of speakers at prestigious conferences, the membership of government committees, and the names of those whose comments were solicited by the media look very different today than they did in the 1960s and '70s. To put it crudely, although in the 1960s a journalist writing on issues related to cloning or sperm banking might choose to interview a scientist, a journalist writing now about issues related to CRISPR/Cas9 would likely

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19 CLARKE notes that: "the disability rights groups were quite vocal in discussing these topics in a very broad public agenda. I think professionally that led into a desire to emphasize non-directiveness as a way of distancing ourselves from the more public-health driven screening programmes. One can see how that shift towards non-directiveness was a way of preserving one's dignity as a profession and was, I think, synergistic along with the development of the genetic counselling community." (*apud* HARPER; REYNOLDS; TANSEY, 2010, p.75).

turn — or also turn — to a bioethicist. Today's journalist might also seek the views of a representative of a patient/parent advocacy group, such as one of the Down syndrome associations, or of an organization that takes a critical approach to genetic technologies, or of a disability-rights group. Thus, the elites whose opinions were sought were replaced, or at least partially replaced, by other elites.

Moreover, we do not know how representative either elite was or is of non-elite opinion. After all, intellectuals' views often differ from those of ordinary people (Nussbaum, 1997, p.127). In the domain of reproductive genetics, surveys conducted in the mid-1990s showed that most physicians and members of the American public considered it unfair to the child, to siblings, and to society in general to knowingly run the risk of having a child with a serious genetic disease, and also that there was a wide gap between the views of geneticists and those of laypersons on reproductive issues (Wertz, 1997a, 1997b; Wertz; Fletcher, 2004).<sup>20</sup> Thus, when it comes to understanding apparently shifting norms in this domain, we need to be attentive to the fact that, as discussed at the beginning of this essay, people may be reluctant to express what they consider — rightly or wrongly — to be aberrant views. If virtually the only opinions that are publicly-articulated reflect the sentiments of selected elites, ordinary people may well be mistaken about what most others think and hence the social price they would pay for dissent. We should thus not be too surprised if new technological, legal, or other developments embolden dissenters to reveal private judgments contrary to those now thought to be near-universal. Should their numbers reach a tipping point, we might find that commitments to today's apparently entrenched norms are in fact weak, and that they will be abandoned as readily as those they only recently replaced.

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<sup>20</sup> Wertz and colleagues found that 81% of patients — as opposed to only 10% of geneticists — believed that people at high risk of transmitting a genetic disease should not have children unless they were willing to use prenatal diagnosis and selective abortion. WERTZ, 1997a, 1997b.

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