Jan Coe

PGD and Genetic "Purification": A Briefing

The contention that the utilization of services such as preimplantation genetic diagnosis (PGD) and selective abortion would reduce the burden on society for caring for very disabled people while freeing funds to support less-disabled persons is debatable. One might similarly ask whether the utilization of radical mastectomies by women has lead to more funding for breast cancer research. The two are not necessarily, or causally, related. The more compelling implicit question is whether utilizing PGD may amount to practicing "genetic purification."

To examine this claim thoroughly, one must declare at the outset: it depends upon who you ask. As with most complex, multidimensional problems, the answer is likely to be different according to who is given voice.

This discussion will enlist the voices from three groups: 1) people with disabilities (although it is acknowledged at the outset that there is no such homogenous entity as "the disabled community"), 2) bioethicists, 3) social scientists and health/medical personnel. Addressing facets of the claim may yield an incremental construction for an answer more rich and nuanced by being constituted from different stakeholders.

~~~

The Council on Responsible Genetics, a non-profit organization that fosters public debate about the social, ethical and environmental implications of genetic technologies, sees the lack of a "bright line" between selection against disability, condition, or trait as a problem. "Routinizing the practice of testing can open the door to termination of individuals for a great many characteristics, including non-medical ones like sex selection" (2001, CRG). The Council believes, as the scenario suggests, that such routinizing will lessen people's acceptance of unusual characteristics and lead to devaluing the people who exhibit them. They point out that the attempt to eliminate disabilities through PGD and/or selective abortion is misguided in any case because a majority of disabilities are acquired through accidents and other environmental causes. Rather than forcing women and families to become "quality control agents," the CRG feels that they should be assisted by economic and social supports to enable them to raise disabled children without going broke.

An argument often made by disability activists is that the so-called medical model characterizes disability as a source of suffering, a deviation from the "norm," an illness or a condition that needs to be treated or cured. Yet there is much evidence that disabled people themselves do not feel this way. In a table that compares self-esteem ratings by non-disabled people, non-disabled people imagining themselves with a severe spinal cord injury, and members of a spinal cord injury survivors group, Gregor Wolbring shows that people with actual spinal cord injury have significantly higher feelings of self esteem that do people who only imagine how they would feel if they had that injury. Strikingly, 95% of the survivor group agreed with the statement "I feel that I am a person of worth," while only 55% of those imagining themselves with spinal cord injury (SCI) did. 83% of those imagining themselves with SCI agreed with the statement "At times I feel no good at all," but only 39% of people with actual spinal cord injury did. And these are not isolated findings (Wolbring, 2002, p.28)
~~~

In contrast to a medical model, disability activists advocate a social model of disability which sees the actual condition, be it Down syndrome, cystic fibrosis, achondroplasia or deafness, as an impairment; the "disability" relates to the array of barriers, attitudes and lack of opportunities that a disabled person faces in society. This model does not deny that the biological realities faced by disabled people are insignificant, but it views them more on a continuum of difference rather than abnormalities. For example, the Canadian Down Syndrome Society "redefined" the definition of DS in 2003. They state that:

> Down syndrome is a naturally occurring chromosomal arrangement that has always been a part of the human condition… Down syndrome is not a disease, disorder, defect or medical condition. It is inappropriate and offensive to refer to people with Down syndrome as "afflicted with" or "suffering from" it. Down syndrome itself does not require either treatment or prevention… The sole characteristic shared by all persons with Down syndrome is the presence of extra genetic material associated with the 21st chromosome. The effects of that extra genetic material vary greatly from individual to individual. Persons with Down syndrome karyotypes may be predisposed to certain illnesses and medical conditions, but that genetic arrangement does not guarantee their development. The same illnesses and conditions are also present in the general population. Timely and accurate diagnosis and appropriate treatment of these illnesses and conditions improves both the length and quality of life, to the same extent as would be expected in the population without Down syndrome… (CDSS, 2003).

When viewed through the social perspective of disability activists, it is clear that what drives the move to prevent children being born with a disability is the discrimination experienced by disabled people (Shakespeare, 2005). Fear of how they would cope with the demands of a disabled infant and cognizant of the negative stereotypes that attend to seeing disabled people in public, it is understandable that many parents would choose to avoid having a disabled child. And yet, as Shakespeare notes, "while the question of disability is individualized and privatized, the broader question, about how society supports disabled children and their families, is neglected" (Shakespeare, 2005, p. 47).

Whether multiple "individual" decisions by parents utilizing PGD to choose non-affected embryos will ultimately give rise to eugenics in the societal or population-based sense is contested. Part of what muddies the situation is the issue of autonomy – the idea that individual women (and parents) should be able to choose to terminate a pregnancy based on their own personal values and beliefs. Some disability activists would say that such autonomy is illusory because genetic counseling by medical personnel is one-sided and based primarily on medical perspectives. Parents are thus predisposed to negatively view the choice to have a disabled child. Pilnick (2002 cited in Pritchard, 2005) states that prenatal screening is undertaken with the principle of informed refusal, rather than informed consent. Pilnick argues that women are obliged to become increasingly dependent on the medical profession through the medicalization of pregnancy. And although genetic counselors strive to be nondirective, the mere fact that such

counseling exists in a medical context is part of the message. Later on, we will see that Rapp (1998) and Wertz (2000) show the medical establishment is not unchallenged by parents, however. Many interpretations and internalizations confound a single framework in which to understand the meaning of disability.

~~~

For another perspective on the issue of PGD and genetic purification, we turn now to the views of bioethicists. The same caveat applies here – there is no one view or model that prevails. Along a continuum of the acceptability of PGD, there are several positions to be found. Savulescu (2001) provides a rationale for accepting what he terms the "eugenic" selection of embryos afforded by PGD by employing his principle of "Procreative Beneficence." This principle makes genetic testing a moral obligation, for parents should select the child of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information (Savulescu, 2001, p. 415). This view seems to place an inordinate confidence in presumably scientifically-derived "relevant" genetic information. All things being equal, he says, why not select the embryo with no predisposition to asthma, for example. This is extraordinary because, even *if* a gene for asthma (or any other trait or condition) is found in the DNA of the embryo, its mere presence is not sufficient to cause the disease to develop in the child. Savulescu then effects a fine tuning of his argument by stating that it is not asthma, per se, which is important, but its impact on a life in ways that matter which is important (p. 419). The best life, according to Savulescu, is the life with the most well-being. Through a circuitous route by reference to various theories of well-being, it seems that Savulescu understands the best life to be that defined by a person who is capable of understanding that they enjoy the best life possible.

Moving to a defense of his views against the "Disability Discrimination Claim," Savulescu uses a hypothetical rubella epidemic to argue that doctors should encourage women to use embryos which they produced prior to the epidemic in preference to ones produced during the epidemic. The reason is that "it is bad that blind and deaf children are born when sighted and hearing children could have been born in their place" (2001,p. 423). Bad for whom, or to whom, one wonders. No doubt to temper the baldness of this statement, Savulescu adds in the following sentence that to say this does not necessarily imply that the lives of those with disability are less deserving of respect and are less valuable. "It is important to distinguish between disability and persons with disability." He offers the comment that no doubt gave rise to this scenario: "there are better ways to make statements about the equality of people with disability (e.g. we could direct savings from selection against embryos/fetuses with genetic abnormalities to improving well-being of existing people with disabilities)" (2001, p. 423). As noted at the beginning of this discussion, the notion that 'savings' would accrue from PGD techniques is highly questionable, and that these hypothetical savings could be directed to improving the well being of disabled people flies in the face of current reality.

A vastly different perspective on disability is offered by Tom Koch. The medical model of disability is an outcome, he says, of "an ideology defining the limited variations permitted in the construction of difference in contemporary society" (Koch, 2005). As with elements of the Savulescuian notion of well-being, the medical model posits "an individual as a discrete, self-reliant, self-conscious person with a store of goods at least equal to others' in society. To be
~~~

disabled is thus to have a lesser endowment, to be unable to experience the world in a way similar to that of other, similarly discrete individuals" (Koch, 2005, p. 124). In opposition to the 'ideology of normalcy,' Koch favors the ideology of difference, in which "all discrete individuals are by definition assumed to be incomplete and un-able, gaining full personhood only interpersonally and socially" (2005, p. 124). Similar to the studies mentioned by Wolbring in the previous section, Koch finds that the claims by disabled people that their lives were full and equal "were assumed to be not rational but *rationalizations* because their insistence violated assumptions of bioethical and clinical life quality based on a standard of mundane normalcy" (2005, p. 127, italics in original). While his position on the termination of embryos through PGD is unknown, it can be inferred to be the same as his position on abortion, euthanasia, and suicide: that they are based on 'negative deviations from the mundane norm' and thus cannot be supported.

Peter Singer is a bioethicist who riles a good many people, not the least of whom are disability activitists. In a response to Koch's article, he takes the opportunity to set the record straight regarding what have been regarded as his controversial views on disability, and in particular, disabled fetuses or infants. Singer makes a distinction between a person living with a disability, which he would support fully in terms of integrating into the community and in living and working as 'normally' as they possibly could, and a fetus that has a gross disability (such as anencephaly) because the fetus would have no chance of becoming a unique, rational, self-aware being (Singer, 2005). On the other hand, he does not believe that newborn infants have the capacities that distinguish a fully grown, rational, self-aware human being nor does he believe that the *potential* of a being is enough to make it wrong to kill that being (2005, p. 131). This seems to allow a lot of leeway for disposing of fetuses and newborns, however. If the criteria of being and personhood do not inhere until adulthood (or near adulthood), surely Singer would not condone the killing of children or teenagers! Singer skirts this implication by stating that "the fact that a being is capable of understanding that it has "a life," and of having hopes and plans for how that life will go, does make it worse, other things being equal, to end that life" (2005, p. 131).

A call for an agenda for bioethics on disability was made by Kuczewski in 2001. Without going into all five convictions to guide bioethicists that Kuczewski enumerated, it is helpful to consider some of the peer commentaries that accompanied his article. In particular, Alan Regenberg dissects the quote that headed the Kuczewski article:

> If I were listing the most dangerous people in the U.S. today, bioethicists, aka medical ethicists, would top my list – way above skinheads, whose beliefs they appear to share. -- (1994, Alice Mailhot, notdeadyet.org)

Regenberg makes the point that academic bioethicists are often guilty of writing for their academic audiences in ways that are likely to mislead and enflame parties not familiar with that style of discourse. In particular, Singer's "sin" was failing to adapt his claims to an "appropriate format capable of responding to the vociferous critiques of his detractors" (Regenberg, 2001). Regenberg does not consider the merits of the various claims, but rather highlights the need for bioethicists to access the skills needed to bridge gaps between concerned parties in these ethical debates, something that Wolbring, in his commentary reiterates once again. As he pithily notes,

"we would not accept a debate about women's health without women being present, and in the same spirit we should not accept a debate about bioethical issues without disabled people present (Wolbring, 2001, p.2). For his part, Singer's commentary on Kuczewski's article raises a valid, but uncomfortable point. He asks rhetorically, who decides [about quality of life] for those with profound intellectual disabilities? There has been a tendency, Singer continues, for people with physical disabilities, but normal intellectual abilities, to regard themselves as spokespeople for those whose intellectual disabilities preclude them from representing themselves. "It isn't clear to me why the fact that an articulate, intelligent person is in a wheelchair makes that person a better representative of someone who has profound intellectual disabilities than someone equally articulate and intelligent who is able to walk unaided" (Singer, 2001, p. 56).

Here it seems we come to the crux of why the issue of disability (not to mention disability and PGD and genetic purification) is so troublesome: writers do not generally pre-define their conceptions of disability – which can obviously range from minor physical features like cleft palates or mongoloid features to severe mental retardation with few outward "abnormal" characteristics. Infants with gross deformities such as anencephaly are lumped in with spinal cord injuries, cerebral palsy or cystic fibrosis. Most of the medical vs. social debate is referring to disabilities that allow at least some percentage of assisted functioning. Unless it is clear that one is speaking, as Singer often does, of profound disabilities, people can continue to speak at cross purposes. Additionally, outside of the bioethicists' and disability advocates' camps, the main concern for parents may be not 'normality' but the appearance of normality that counts. To consider why this may be so, we can turn to a rich literature generated by social scientists such as anthropologists, child psychologists and psychiatrists, genetic counselors, clinical geneticists, and health economists, which form the next section or perspective on the claim.

~~~

In order to address the views from social scientists, I have subdivided them into two categories: those writers that report on actual studies <u>with</u> disabled people or parents/prospective parents of disabled children, and writers who thoughtfully speculate on the outcomes, implications, and fears that genetic advances and reproductive techniques will mean for future generations.

Starting with the work on amniocentesis by Rayna Rapp, it is apparent that the "lived experiences of reproduction" need to be consulted as there is no universal explanation of why some women are able to integrate a disabled child into their families and some try to prevent it. Rapp makes a strong case for the insights that families with disabled children can contribute to scholarship. Here, she says, "religion, ethnicity, class and family history powerfully shape responses to having a child with a genetically stigmatized condition. Reflections on the meaning of maternity and paternity and the value of children are embedded in the stories parents of the disabled tell as they transform medical diagnosis into the social fabric of daily life" (Rapp, 1988). Her 1998 article on refusing prenatal diagnosis is filled with grounding details arising from narratives that capture the variety and logics that women and families use to make sense of positive diagnoses of disability.

Class differences (finely calibrated, however), ethnicity, previous reproductive history, gender relations, familiarity with the statistical delivery of risk information given by genetic counselors
~~~

– all play a part in how a woman internalizes and acts (or does not act) on the prospect of bearing a disabled child. Paradoxically, for a condition such as Down syndrome, about which there is both ample information and advocacy/support groups, there is also a very high – 90 to 95% - abortion rate. Rapp tells the story of a certain young woman (whose family included a sister with spina bifida) that became pregnant and went for prenatal tests. Relieved that her fetus did not have spina bifida, the young woman was philosophical about the prospects for her child – which *was* diagnosed with Klinefelter's syndrome. Growth problems, sterility, and possible learning disabilities or mild mental retardation are features of Klinefelter's, but these problems were less salient when the young woman was told that her son would "look normal." As Rapp puts it, it was the relative invisibility of the consequences of her son's atypical chromosomes that made them normal in her estimation (Rapp, 1998, p.64).

There is something in this story that resonates with Koch's ideology of normalcy in terms of the exception proving the rule. Were there not unambiguous pressure to adhere to the accepted norm, especially in physical presentation of symptoms, people might be more forgiving of deviations from that norm, especially since greater anomalies may hide within a "normal" body.

Götz and Götz (2006) provide additional complexity to the question about how parents react to prenatal diagnosis and PGD. Their study of parents of children with cystic fibrosis who were initially determined to use prenatal testing but eventually refused it allowed them to posit a model of change that contextualizes and refutes the proponents of more static models of disabilities. Among the explanations given for their change of heart, parents mentioned seeing their first child grow and develop favorably in many ways, gaining experience with the disease, and feeling more confident with the management of its complex treatment (2006, p. 295). It is also instructive to follow the stages in their model of change. Beginning at stage 1 with information and counseling, through stage 2 to what can be a lengthy period of absorbing information and developing new concepts, the crunch comes at stage 3, when a pregnancy means that action is required. Götz and Götz found that many parents – faced with the choice to "play God" ultimately refuse to do so, preferring to delegate decision-making to fate, or, in some cases, God (2006, p. 297). These results call into question the assumption that because parents are now able to select against disability, they will in all cases.

A study showing a preference for PGD among those patients who have undergone previous terminations lends some support to the claim that PGD could be a valuable alternative to prenatal diagnosis -- as well as confirming that the procedure is highly stressful. Lavery and others (2002) received 36 completed questionnaires from 67 they sent to patients who had actually undergone PGD. They found that the main advantage articulated by patients was being able to avoid the "therapeutic" termination of pregnancy (2002, p. 2466). Disadvantages included the low 'take-home baby' rate of 15-20% per cycle started, and cost.

Priscilla Alderson reports from her exploratory qualitative research with 40 adults with congenital conditions, including 5 with Down syndrome, that some people with Down syndrome live creative, rewarding and fairly independent lives, and are not inevitably noncontributing dependents (Alderson, 2001, p. 627). While conceding that her study may have involved exceptionally able people, Alderson is correct that:

> …the potential of people with learning difficulties will not be realised until they have many more opportunities to develop it. Research which enquires beyond morbidity into people's potential and achievements, and the social influences which support or constrain them, is required before their ability can be assessed realistically. Such research moves on from notions of fixed (dis)ability, static syndromes, expert researchers and inadequate subjects, to acknowledge how the research questions, methods, interactions during interviews, and hidden assumptions about medical or social models of disability, all shape the data (2001, p. 636).

There is a case to be made for more research that examines the social context of the lives of disabled people, much as Shakespeare has done with the AnSWeR web site (Antenatal Screening Web Resource). Alderson raises a troubling point by questioning whether Down syndrome began to be screened because this was technically possible rather than because it was the most serious condition. Before the numbers of Down syndrome people fall through prenatal testing and PGD, she stresses that it is important that more research be conducted to enable broader, more realistic evidence about the range of ability among people with Down syndrome, and about links between intellectual ability, contentment and self-esteem, noting that the general population shows no clear correlations and that life style may be more salient than intelligence to quality of life (2001, p. 636). [This is a point that high profile persons such as James Watson may profit from considering, given his views.]

In a broad-ranging international study, Wertz (1997) surveyed the ethical views of genetics professionals from 37 nations based on their responses to information presented in the form of case vignettes. The surveys took place in 1985-86 and again in 1994-95 and provide a wealth of information, statistics, and cross-cultural comparisons.

The differences are revealing between geneticists, genetic counselors, and patients in terms of which fetal conditions for which they would choose to abort. Of the 24 conditions, a majority of the geneticists, both inside and outside the United States, would themselves abort for 15. In the United States, 85% would abort for Down syndrome, 92% for severe, open spina bifida, 74% for cystic fibrosis, 72% for Huntington disease, and 56% for achondroplasia. A majority of the U.S. genetic counselors would abort for 11 of the 24 conditions, while among patients (91% women) only a small majority would abort for four of the 24 conditions. As Wertz notes in something of an understatement, "the results suggest that there is room for considerable further research on how the different worldviews [among geneticists, genetic counselors, and patients] are mutually understood in the process of counseling, if indeed they are understood" (Wertz, 1997, XI.,¶8).

Pertinent to the topic of PGD and genetic purification, it is worthwhile to go back and consider the encounter with the medical personnel (M.D. geneticist or Master's level genetic counselor) from whom parents first receive the news about a positive diagnosis. On questions relating to nondirectiveness (what Wertz called the "motherhood and apple pie" statement of U.S. genetic counseling) there was no evidence that this is what people really want (1997, IX., ¶4). While parents would resent being told what to do in this context, they also appeared to want more than a 'value-neutral' information machine. Moreover, Wertz says, they want to think that they are

facing a human being who has a set of values and who cares about them and about their own values and concerns.

This dovetails with Rapp's findings that structural reasons for accepting or refusing prenatal testing can even be influenced by the characteristics and staffing of prenatal clinics. Writing about the variation between clinics on the acceptance rates of genetic testing, she notes that in one clinic with a 70-80% acceptance rate, the clinic provided a stable and welcoming environment in which the women tended to feel comfortable and to trust the nurses. At another clinic that had been a 'site of struggle over services' for many years, the acceptance rate was 30–40%. At this clinic the waiting times were long, there was poor professional-patient communication, and it was "much more likely that a woman [would] break a counseling appointment or sit through it in a state of distrust….Acceptance rates are conditioned by the microsociology of access to respectful medical services" (Rapp, 1998, p. 53).

It is worth remembering that before we make assumptions about genetic purification, we need to think about how and in what manner people receive information about genetic testing; and before we make assumptions about their willingness to use a reproductive technology like PGD, we need to think about what circumstances brought them to the clinic or a referral to a geneticist; and before we make assumptions that the information provided by the genetic counselor was ultimately the point at which a decision was made, we need to think about "…economics, women's roles, services for children with disabilities, cultural expectations, availability of contraception, [and] abortion." The point is that there is necessarily not a linear route from diagnosis to test, and from test to more tests and from more tests to genetic purification – the multidimensionality of the issue means that at any point along the way people may choose differently and confound expectations.

The final facets to confront include medical and non-medical factors that may have an impact upon people's willingness and/or capacity to utilize certain reproductive technologies like PGD. These facets include policy issues, the availability of insurance, and the commercialization of testing.

A glimpse at some of the applications to which PGD may be put in the future is outlined by Robertson (2003). His purpose is to look ahead, assuming that current uses of PGD are "ethically and legally acceptable when performed according to applicable regulatory guidelines" (Robertson, 2003, p. 466). Leaving aside the question of the existence and adequacy of 'applicable guidelines,' one of the expanded uses of PGD could include routinizing services for the older patient group (>39 years) such that aneuploidy (abnormal number of chromosomes) analysis becomes the standard of care. Another growth area is likely in PGD for so-called *susceptibility conditions*. Screening for BRCA1 and 2 [breast cancer] susceptibility is mentioned in the context of avoiding the birth of children that face a higher than average risk of having cancer or some other serious disease. Robertson states that PGD may now make it possible to establish pregnancies free of the feared susceptibility condition (2003, p. 467).

In addition, there is now a precedent for using PGD for early-onset Alzheimer's disease, although it remains ethically ambiguous whether a parent who is dominant for the disease should be helped to select a disease-free embryo that they will possibly not live long enough to rear.

Other uses that make headlines every now and then are the so-called "savior siblings" and PGD for sex selection or "family balancing." On the subject of using PGD for expressly non-medical traits, Robertson reasons that "it is too soon to reach definitive judgments about whether these uses, if ever feasible, would or should be permitted…Until they are closer to practical reality, they should not be an important factor in determining the acceptability of more feasible uses" (2003, p. 470).

Unlike the U.K., which has the Human Fertilisation and Embryology Authority (HFEA) to regulate and oversee existing and proposed uses of reproductive technologies, Robertson acknowledges that the situation is quite different in the United States where no agency exists that plays a role comparable with that of the HFEA. Despite this, he states that with PGD, the need for a new agency or more explicit public controls may be less pressing than initially thought. Why? Because "most of the new uses of PGD fit easily into old categories of efforts to ensure that offspring are healthy" (p. 470). At the very least this seems to side-step or gloss over whether, in fact, selection in all cases can be said to amount to ensuring the health of offspring.

The nexus of predictive medicine with insurance is another highly fraught arena, especially in the United States. Van Hoyweghen and others make a compelling case for the shift in focus from "…symptoms and treatment to pre-symptomatic diagnosis and preventative intervention" in the insurance industry (Van Hoyweghen, 2006, p. 2). In their discussion on lifestyle risk factors, they conclude that people with some lifestyle risk factors are seen by insurers as already ill and what is more: as people responsible for causing their own illness and therefore deserving of an extra premium (2006, p.4). On the face of it, this could work disadvantageously if applied to genetic conditions. Parents could feel pressured to ensure that they only produced those children that were at least as healthy as possible at the start of their lives. Surprisingly, Van Hoyweghen reports that – at least in Belgium (where the study was undertaken) – a different scenario obtains. Restricted by law from using family history as a decisive risk factor, people who are at risk for genetic conditions may instead be considered *victims*; their "bad genes" are outside their choice or control (2006, p. 8). In this way, they see in Belgium the institutionalization of 'genetic essentialism'.

In the United States, Kaufert found that violation of privacy and the potential for genetic discrimination loomed large. Among clinicians she found that the underlying and general concern [was] how to counsel testing if the costs must be met out of third party insurance and result in a patient losing both a job and insurance coverage. "It is not the fear of living with the cause of death specified, but very pragmatic considerations of access to health care for oneself and one's family, and having a job" that mattered (Kaufert, 2000, p. 826). Although clearly of concern to citizens, legislation in this regard has stagnated:

> For over ten years, Congress has considered legislation to ensure comprehensive protection for all Americans. The U.S. Senate passed the Genetic Information Nondiscrimination Act of 2003 (S.1053) [thomas.loc.gov] in 2003 by a vote of 95-0, but an identical bill was never introduced or passed in the House and the bill did not become law. A similar Senate bill, the "Genetic Information Non-Discrimination Act of 2005" (S.306), passed 98-0 in February 2005. Representatives Judy Biggert (R-IL), Louise Slaughter (D-NY), Bob Ney (R-OH),

> and Anna Eshoo (D-CA) introduced an identical bill H.R. 1227, in the House, on March 10, 2005. Currently the bill is being considered by three House committees - the Committee on Education and the Workforce, the Committee on Energy and Commerce, and the Committee on Ways and Means. (NHGRI, 2006).

If the pace of government action in legislating against genetic discrimination has been glacial, the same cannot be said for the genetic testing industry. Relative to earlier practice, Kaufert finds, "…commercialization has…dramatically changed the context of testing, stripping it out of the clinic and removing the intermediary roles of geneticists and genetic counselor" (2000, p. 823). Direct-to-consumer tests over the Internet have proliferated. This phenomenon so concerned the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) that they wrote in 2004 to the Secretary of Health and Human Services, Michael O. Leavitt, expressing "…a strong concern that the promotion of such tests to consumers could be harmful if a health professional is not involved in the process" (SACGHS, 2006). The outcome two years later is that two inter-agency work groups have been formed to monitor claims made by companies advertising genetic tests on the Internet and to evaluate the public health impact of DTC marketing of genetic tests.

Some of the impacts upon people's willingness and/or capacity to utilize certain reproductive technologies like PGD may be quite tenuous, such as whether the rise in numbers of genetic tests will substantially lead - if not to "designer babies" - then at least to a desire for "normal" i.e. non-disabled babies in all cases. There is more at stake than a slippery slope argument in these debates. Whether the use of PGD will reduce society's burden in having to care for very disabled people may also turn on what conception of society we favor living in.

~~~

From this review of perspectives from disabled people, bioethicists, and social scientists and others, it is clear that - at the very least - the path from using a reproductive technology like PGD does not inexorably lead to genetic purification. The pressure to bear children who do not have a disability might be balanced by research into the lives of disabled people that will give needed information to those who doubt their ability to care for a child with special needs. Bioethicists may take up Kuczewski's suggestion that bioethicists imitate the legal profession and devote 5-10% to pro bono work in areas related to disability: independent living, long-term care, rehabilitation care, and care of the indigent (Kuczewski, 2001, p.38). Certainly they should seek out and nurture an ability to translate debates so that more views may be considered and claims may be accurately appreciated and critiqued, as Regenberg suggests (2001). Genetic discrimination as an issue of importance to all may be addressed in the *next* administration. All of these things are possible.

The most important wedge against genetic purification may also be the sheer numbers and variety of individuals and couples who have a stake in allowing whether a deterministic future will go forward. Each individual decision is important and each individual decision cannot be predicted just by reference to the available technologies. Richard Ashcroft says, "…while we might regard individual choices and societal change as disconnected, or our evidence so poorly predictive of the connection between the two as ("from a policy point of view") better ignored, this seems to me a moot point. What sort of society would it be like if we all chose in such ways? Or wanted to (even if we were unable to do so in practice, or only few of us were)? One cannot
~~~

simply dismiss this question as not susceptible to a scientific answer. It is surely just the sort of question philosophers and society at large are responsible for answering. **For in the answer lies the material for bringing the answer into effect**. (Ashcroft, 2003, 219, my emphasis).

If the answer tilts toward variation and tolerance, we will find that we have the means to make that a reality.

References

Alderson, Priscilla. (Sept 2001) Down's syndrome: cost, quality and value of life. *Social Science & Medicine, 53* :627. Retrieved 2 June 2006, from Health Reference Center Academic database.

Ashcroft, R. (2003). Bach to the future: response to: extending preimplantation genetic diagnosis: medical and non-medical uses. *Journal of Medical Ethics, 29*.4: 217.

Canadian Down Syndrome Society. (2003). *Down syndrome, redefined*. Retrieved on 6 June 2006 from http://www.cdss.ca/en/main.htm

Council on Responsible Genetics. (2001). *Predictive testing position paper*. Retrieved on 6 June 2006 from http://www.gene-watch.org/educational/predictive_testing.pdf

Götz, I. and Götz, M. (2006). How and why parents change their attitudes to prenatal diagnosis. *Clinical Child Psychology and Psychiatry, 11* (2):293-300. Retrieved on 5 June 2006 from Highwire Press Journals.

Kaufert, P.A. (2000). Health policy and the new genetics. *Social Science and Medicine, 51*:821-829. Retrieved on 4 June 2006 from Science Direct.

Lavery, S.S., Aurell, R., Turner, C. et al. (2002). Preimplantation genetic diagnosis: patients' experiences and attitudes. *Human Reproduction, 17*(4):2464-2467. Retrieved on 5 June 2006 from Highwire Press Journals.

Koch, T. (2005). The ideology of normalcy. *Journal of Disability Policy Studies, 16* (2):123-129. Retrieved on 6 June 2006 from Academic Search Premier database.

Kuczewski, M. (2001). Disability: an agenda for bioethics. *American Journal of Bioethics, Summer, 1*(3): 36-44. Retrieved on 6 June 2006 from Academic Search Premier database.

National Human Genome Research Institute. (2003). *Legislation on genetic discrimination*. Retrieved on 15 June 2006 from http://www.genome.gov/10002077.

Pritchard, M. (2005). Can there be such a thing as a 'wrongful birth'? *Disability & Society, 20*(1):81-83. Retrieved on 4 June 2006 from Academic Search Premier database.

Rapp, R. (1988). Moral pioneers: women, men and fetuses on a frontier of reproductive technology. *Women and Health, 13* (1/2): 101-116.

Rapp, R. (1998). Refusing prenatal diagnosis: the meanings of bioscience in a multicultural world. *Science, Technology, & Human Values, 23* (1):45-70. Retrieved on 2 June 2006 from JSTOR database.

Regenberg, A. (2001). *American Journal of Bioethics, Summer, 1*(3):1-3. Retrieved on 6 June 2006 from Academic Search Premier database.

Robertson, J.A. (2003). Extending preimplantation genetic diagnosis: the ethical debate. Ethical issues in new uses of preimplantation genetic diagnosis. *Human Reproduction, 18* (3):465-471. Retrieved on 4 June 2006 from http://humrep.oxfordjournals.org/cgi/reprint/18/3/465

Savulescu, J. (2001). Procreative beneficence: why we should select the best children. *Bioethics, 15* (5/6):413-426. Retrieved on 4 June 2006 from Academic Search Premier database.

Secretary's Advisory Committee on Genetics, Health and Society. (2006). *SACGHS Letter to the Secretary of Health and Human Services* (February 8, 2006). Retrieved on 15 June 2006 from http://www4.od.nih.gov/oba/sacghs/reports/reports.html#direct

Shakespeare, T. (2005). Solving the disability problem: whose responsibility? *Public Policy Research, 12(*1): 44-48. Retrieved on 4 June 2006 from Academic Search Premier database.

Singer, P. (2001) Response to Mark Kuczewski. *American Journal of Bioethics, Summer, 1*(3):55-56. Retrieved on 6 June 2006 from Academic Search Premier database.

Singer, P. (2005). Ethics and disability: a response to Koch. *Journal of Disability Policy Studies, 16* (2):130-133. Retrieved on 6 June 2006 from Academic Search Premier database.

Van Hoyweghen, I., Horstman, K. and Schepers, R. (2006). Making the normal deviant: the introduction of predictive medicine in life insurance. *Social Science & Medicine*, [article in press]. Retrieved on 4 June 2006 from Science Direct.

Wertz, D. (1997). *Society and the not-so-new genetics: what are we afraid of? Some future predictions from a social scientist.* Retrieved on 6 June 2006 from http://www.umassmed.edu/shriver/Research/SocialScience/Staff/Wertz/lawjrl.htm

Wolbring, G. (2001). Disabled people's approach to bioethics. *American Journal of Bioethics, Summer, 1*(3):1-3. Retrieved on 6 June 2006 from Academic Search Premier database.

Wolbring, G. (2002). *Science and technology and the triple D (disease, disability, defect).* Converging Technologies for Improving Human Performance. Section C: improving human health and physical capabilities. Retrieved on 4 June 2006 from http://www.technology.gov/reports/2002/NBIC/Part3.pdf :206-216.