Reading SAL on Prenatal Genetic Testing

AMA Council on Ethical and Judicial Affairs

It is ethically permissible to genetically select to prevent, cure or treat disease. It is not ethical to select on the basis of benign characteristics. Genetic manipulation of benign traits is only permissible if there is clear benefit to the child, no tradeoffs with other characteristics and equal access to the relevant technology without consideration of socio-economic factors.

Human Genome project may change things. Currently couples at high risk for genetic disease can (1) choose not to reproduce, (2) ignore the risk, (3) have prenatal diagnosis [amnio, CV] or (4) ART [artificial insemination or surrogacy; IVF and PID]. Genetic manipulation is currently impossible.

Ethical issue: to define the role of medicine with respect to the role of parental choice (which we tend to think of as 'private'); relation of selective to elective abortion; effects of genetic engineering on human relations; and the importance of medical/ scientific uncertainty in answering any of these questions.

Prenatal Genetic **Testing** (PGT) and Pre-Implantation Genetic Diagnosis (PID or PGD) expand the range of parental options [=to continue this pregnancy, to attempt to bear this or that child]

- reduce or ameliorate suffering
- early detection of potentially life-threatening or disabling conditions
- expansion of life-chances

But also represent some potential disadvantages:

- possible abuses
- inefficient use of health care resources
- exacerbation of discrimination [eg. xyy and violence; sex selection; devaluation of living exemplars
- tendency to 'eugenics' mind-set
- 'commodification' of children: analogy c a dell computer

Role of the physician: Medicine's primary function is to prevent or treat disease. There has been some expansion of that role [cf. cosmetic surgery]—but we must be very careful to avoid misuses. Selective abortion is a case in point. It is appropriate only to 'correct or avoid unambiguous disabilities or to improve the well-being of the fetus.' Sex selection, for instance, is not allowed. "The justification for abortion weakens as the disease to be avoided becomes milder."

- but: physicians can only go so far in inferring parents' reasons

Testing itself is not without risks; so people who request testing should be informed of them. All information derived from tests should be conveyed to the parents (even if you are not sure what they will do with it) for they, not the fetus, are the patient.

Genetic **Manipulation** is not currently possible; but current advances in genetics make it a future possibility. Genetic extension of medicine's current means of correcting functional abnormalities is still within medicine's proper scope. There is some debate, however, about whether somatic-cell is the only appropriate manipulation, or whether germline manipulations are also allowable. Problems:

- uncertainty about possible effects
- tampering with mankind's 'genetic heritage'
- gives present parents too much control over future generations

In any case the ethical constraints are clear: only to treat or cure disease, and then only with caution; and never to manipulate benign traits (for fear of the serious threats of discrimination and eugenics).

Conditions: Must be clear and meaningful benefit to the child who will be born.
No trade-off with other characteristics or traits (which means we have to know a lot more than we do now). And access to any such technologies would have to be irrespective of income or other socioeconomic characteristics, so as to prevent widening the (already huge) gap between haves and have-nots. These are minimum (not exhaustive) tests of ethical propriety.

Asch: Prenatal Diagnosis and selective abortion: A Challenge to practice and policy (1999)

Prenatal tests for fetal disabilities are standard of care for women over 35 yo without much consideration of what this policy communicates about societal and familial acceptance of diversity in general and disability in particular.

Disabilities and chronic illnesses [identified throughout this article] are assumed to be incompatible with life satisfaction. But Asch argues that (1) most of the disadvantages of disability stem from social arrangements [and attitudes] that, like racism or sexism, can be confronted and changed, rather than blindly accepted and acceded to. Further, (2) PGT and selective abortion are offensive in a way few other disease prevention techniques are.

(1) Health, disease and 'normalcy' are to some extent culturally determined, and to some extent statistical constructs. Health professionals tend to adopt an attitude toward the statistically or 'norm' anomalous that is based on two false assumptions: that the life of a person with a chronic illness or disability has a 'disrupted' life (as if they had a leg cramp or a bout of diarrhea); and that if such a person suffers isolation, powerlessness, unemployment, poverty or low social status it is the biological condition that is to blame.

. This misunderstands the extent to which h/illness are experienced as deviations from the baseline—not as attributes OF the baseline. [A blind person is ill when she has pneumonia, but healthy when she does not, even if blindness is not 'species normal'.]

. And it contributes to a tendency to ascribe problems that occur to people with disabilities to the disability, not to external factors. But the new paradigm is to look instead at how societal arrangements [rules, laws, means of communication, characteristics of buildings and transit systems, requirements of workplaces] exclude some from participation in social goods, and how they might be altered to be more inclusive.

(2) There is a profound difference between (a) preventing the disability or illness of a born or future human being [like prenatal care for pregnant women, or public health measures to clean up the environment, use seat belts, reduce smoking…] and (b) preventing the birth of a human being who will have an undesired characteristic. Prenatal diagnosis and selective abortion for disability conduce to the belief that all you need to know about a fetus [and thus a future human being] is whether s/he will be disabled in order to write off the value of that life and that person. It says that it is better to not exist than to live with a disability. Further, endorsing the technology of prenatal diagnosis may be inconsistent with working to improve social justice and equality for people with disabilities.

Rationales for prenatal testing

Some say the cost to the child, the family and to society of childhood disability is the justification for prenatal testing. But the disabilities thus found are but a small proportion of disabilities, and the cost savings is trivial. Further, most of us will at some point in our lives become more or less disabled. Encouraging a society that disvalues disabled individuals is of little profit compared to its costs: namely, the moral costs of denying the disabled a place in the human moral community.

The "right to an open future:" Some people argue that it morally wrongs a child to bring a child into being with a less than ideal health status or reduced life options. But Asch argues that most disabilities preclude far fewer life possibilities than [bioethicists] think; that empirical evidence suggests that many, if not most, disabled people are more satisfied than average with their lives; and that most dissatisfactions are with disparities in attainment that could be removed by social accommodations and inclusion

Nor does she accept the argument that families are ruined by the birth of a child with disabilities. The 'extra burdens' of a disabled child are no worse than the 'extra burdens' of a gifted child, and all children are equally sources of stimulation, love, companionship, pride and pleasure. Stress, family disruption and frustration are neither unique to childrearing of disabled family members, nor avoidable through prenatal diagnosis. There is empirical evidence that the more experience families have with people with disabilities, the less interest they have in prenatal diagnosis and selective abortion.

Professionals developing, offering and interpreting tests should be careful that they are proceeding on the basis of information and experience, not bias. People who are receiving counseling on results of PGT need information on laws and support systems for specific disabilities as well as a description of the impairments; and literature by families with disabled children and by the disabled people themselves. Professionals should also realize that just as not all disabled individuals are the same, families are not the same either, and their own individual situation and attitudes should be explored.

Further, they need to continue to work to change the society in which disabled people are being raised: inclusive education, access to programs and services; reform of reimbursement practices of insurance and social support. When a child with disability is not a problem for the world, and the world is not a problem for a child with disability, we may be able to reduce our need for and utilization of prenatal testing and selective abortion.

Steinbock: Disability, Prenatal Testing and Selective Abortion (2000)

[Steinbock responds specifically to Asch and some 'disability rights' arguments.]

"Forms of variation:" Some disability activists claim that disabilities are like variation in sex or skin color: a variation rather than a disability, and just as feminists consider sex selection abortion discriminatory and offensive, disability activists consider selective abortion for disabilities discriminatory.

"Disability perspective:" Instead of eliminating people with disabilities, we should devote our efforts to changing the way society views them. (NB: this position is not necessarily a 'pro-life' position; it claims abortion to terminate a pregnancy is different than specifically deciding against this specific fetus on the grounds of a disability.)

I: Are disabilities neutral variations?

BS argues that we should be able to consider (some) disabilities a medical issue, even though you can have a disability and be healthy. Disabilities are not necessarily disadvantaging, but they may be; you can have a disadvantage and not be disadvantaged…We can separate disadvantage and discrimination, so we don't have to insist that disabilities are morally neutral variations.

II: Are disabilities medically or socially constructed?

The WHO distinguishes 'impairment' as an abnormality or loss of structure or function;
'disability' as the consequence of an impairment; and
'handicap' as the social disadvantage resulting from impairment or disability. It's clear that the degree of handicap is a socially malleable variable, but the same need not be true of disabilities. Further, not all disabilities can be ameliorated by social arrangement even if we did pay more attention to social arrangements.

III: What is the morality of attempting to reduce the number of disabilities?

BS argues that there are many ways of reducing the number of disabilities (ie, iodine in salt, recommending/forbidding some things to pregnant women…) and we don't condemn most of them.

But selective abortion for disabilities seems to be more problematic. There's a difference between actions that prevent individuals from becoming disabled—and actions that prevent disabled persons from being born.

IV: Disability perspective on prenatal testing for disabilities:

Testing is as discriminatory as selective abortion. It expresses the mistaken belief that life with a disability is not worth living. It can't predict or prevent all disabilities anyway, so an attitude of inclusion is more useful than an attitude of removal. And such testing encourages people to believe that a 'perfect baby' is possible—increasing discriminatory attitudes toward disability,

BS argues that selective abortion is really just 'preventative,' like putting iodine in salt to prevent goiter. *[This is not very persuasive. In fact, it's pretty silly.]* She then (p. 691) proceeds to tie her argument to one position on the acceptability of abortion: "if abortion is permissible at all, it is permissible to avoid such outcomes, or the risk of such outcomes." (p. 692)

Asch denies that prenatal testing and selective abortion or embryo selection are 'preventative.' BS, for her part, denies that people who are unwilling to welcome and nourish a child with disabilities are morally deficient. She suggests that a society can both attempt to prevent disability and provide for the needs of those who are disabled.

Botkin: Ethical issues and practical problems in PID (1998)

[Asch talks about prenatal diagnosis and selective abortion. Botkin addresses a new ART that avoids abortion: selection among fertilized eggs to determine which should be implanted for development.]

PID is being described as a less morally problematic alternative to PGT because it avoids abortion. Maybe so: but it raises other ethical issues, even in comparison with the PGT.

. IVF is complex and involves incredible stresses on the women who undergo it
. It is experimental and expensive, and won't ever be covered by insurance

So far most cases of PID are done in connection with IVF for other reasons (=infertility)

"How many women would spend $40,000 for a procedure with a 5% success rate to ensure an outcome that would occur 97.5% of the time anyhow?"

The traditional path would cost under $3,000, and then only if an abnormality was detected.

There is some ambivalence about PGT in some populations—ie CF and Sickle Cell.

Also there is ambivalence about PID that does not reduce to ambivalence about PGT. All this suggests that it will be at best a boutique service for the foreseeable future: we may build it and discover that they *don't* come.

PID does not cause an increase in congenital disabilities—but diagnosis for any specific configuration does not reduce the possibility below baseline for untested disabilities.

There are two differences between advantages claimed for PGT and PID:

. It's not just 'information gathering/communication.' The 'non-directive' counseling appropriate for PGT seems inappropriate for PID.

. It's not just to 'prepare parents for the birth of an affected child.' That too is inappropriate in the context of PID.

Ethical issues:

(1) destruction of prenatal life: positions on the issue of the moral status of prenatal life range from conception (=some religions) to 18 months old (=some philosophers). So whether destruction of prenatal life is a problem for you depends on where you believe [life? human life? morally relevant life?] begins. [The current main-line position seems to be that prenatal human life has a special moral status, but one that is not equal to that of a 'full fledged' person.] = 'developmental' conception of moral status.

For the conservative position, PGT is problematic if it leads to selective abortion. But for that position, PID is even more problematic, for it leads to the creation of several pre-embryos for each live birth; and leads to the loss of more prenatal life.

(2) possible expansion of conditions for which prenatal diagnosis is considered socially acceptable—and a social acceptance that will move PID from the lab into the clinic. Asch thinks that drawing any line between 'serious' and 'minor' conditions will disadvantage those below the line…

(3) By producing a number of embryos with each cycle and eliminating the moral hurdle of abortion in the selection of offspring, PID facilitates a broad range of possibilities for selecting the biological characteristics of children—including many traits that have been previously considered up to the 'natural lottery.' "This may be a growth industry in the coming century for couples who can afford it." (p. 540)

(4) One persistent criticism of PGT is the message of rejection that it sends to people with disabilities. Whether PGT [or PID] will worsen prejudice against the disabled is an empirical question, and we are unable to predict its effects. All we know so far is that our society is less prejudiced toward the disabled than it was in the past. It may increase the social expectation of 'perfectibility'; but actually most disabilities now come from non-genetic causes.

(5) What worries Botkin most is the attitude of parents: PID will harden their expectations of children and make it even harder for kids to measure up! It may alter childrens' self-perception as well, stifling a child's feelings of self-determination. *[After all, if your parents had spent a fortune making you the ideal piano player, do you really feel free to prefer the violin?]*

Germ-line therapy and genetic enhancement

PGD could be a component in two controversial interventions that are not relevant to traditional prenatal diagnosis. The ability to manipulate the *in vitro* embryo will greatly facilitate the insertion of genetic material—either to treat or to enhance, cuz insertion into a fetal cell will transform all of the cells of the resulting individual—including the gametes.

Fortunately it's now impossible as well as beyond the scope of this article!

Sandel: Embryo Ethics: The Moral Logic of Stem Cell Research (2004)

> *This is a neat little article. His point (a) basically accuses Kass of inconsistency, and seems to me right on. His argument (b) points out that it is only the people who are against both abortion and ART who are consistent. His argument (c) is misconceived, tho—what I would conclude from that is that we do not honor the prenatal dead sufficiently. Cf. the Japanese customs in this respect.*

Critics of stem cell research argue that (1) it involves the destruction of human embryos and (2) may open the door to other dehumanizing practices.

Sandel suggests that just as acorns are different than mature oaks, so embryos are different than babies, and embryos are not persons. Graduated moral respect is different than moral indifference, tho.

(a) "If harvesting stem cells from a blastocyst were truly on a par with harvesting organs from a baby, the morally responsible policy would be to ban it, not merely to deny it federal funding." (708)
(b) Any argument that would prevent stem cell research will also forbid most ART, esp. IVF.
(c) Natural procreation also entails the loss of some embryos.

George and Lee: Acorns and Embryos (2005)

This article is a response to the Sandel article, and also to another which denies that clones are human beings—a truly weird position.

Noone would object to using stem cells if you didn't have to destroy embryos to get them. G&L consider the main problem to be that embryos are one stage of development of human adults, but they think that Sandel denies that embryos are human. And indeed, Sandel does say (p. 708) that "acorns and oak trees are different kinds of things. So are human embryos and human beings." *(an unfelicitous phrasing, it turns out)*

G&L deny the analogy between oak trees and human beings because the reasons for valuing the oak tree are accidental to its nature – its beauty, age, etc—while we value human beings because all human beings have equal moral worth. What is essential to the embryo is that it is a complete, distinct, human organism. They accuse Sandel of putting greater weight on 'personhood' as evidenced by various mental capacities than on this essential human nature; while they consider 'person' to be attributable to any member of the human community. "The dignity of human beings is intrinsic to the kind of entity we are."

The other object of this article, Paul McHugh, seems to argue that somatic cell nuclear transfer (=SCNT, the process that created Dolly) does not produce human beings. Frankly, that argument seems to me quite dangerous; it could be used to deny moral standing to creatures in every respect the moral equal of human beings.

Cf. Cordwainer Smith