

## The Center for Bioethics and Human Dignity

COMMENTARY

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### **Poor Prognosis for Preimplantation Genetic Diagnosis (PGD)?**

by John F. Kilner

On May 5, 2004, a front-page story in newspapers around the U.S. reported the production of babies to provide bone marrow or umbilical cord blood for their sick siblings. The reproduction process involved producing many embryos through *in vitro* fertilization (IVF), testing them for how well they genetically matched their siblings, throwing away the majority who did not match well, and only implanting some of those who remained. The testing technique used in such procedures is called preimplantation genetic diagnosis, or PGD.

Helping sick children is wonderful and should be a high priority. We ache with their parents and are motivated to do all that we can to help. But once we suggest that accomplishing something good can be pursued using any means necessary, we have crossed an ethical line.

Many people are deeply disturbed by PGD. They recognize that beginning new human lives at the embryonic state, testing them to see how useful they will be, and throwing away those who don't measure up is demeaning—and not just to those who are sacrificed. Those who survive are demeaned as well since they are allowed to live only because they are sufficiently useful to someone else.

Some of the worst medical atrocities to date have been rationalized with the notion that there is something wonderful to achieve and no other way to achieve it (not just the atrocities of Nazi medicine, but also such ethical violations as documented in Henry Beecher's landmark expose in the *New England Journal of Medicine* [vol. 274, pp. 1354-60]). We need to be careful lest misguided compassion move us to pursue a quick fix that will foster a way of thinking that will harm a much larger number in the long run.

Advocates of the process sometimes defend it with claims beyond the argument that PGD is “necessary.” Here are the most common:

1) Some claim that the process avoids the need to abort children later who are not well-matched to their siblings. But, killing developing human beings earlier as opposed to later is no improvement--either way the same human beings die because they don't measure up.

2) Others claim that various risks of the procedure to the child can be mitigated. They argue that unknown risks to healthy embryos from the genetic testing procedure, and the pressure on children born through this PGD process to donate bone marrow irrespective of their will can be addressed through monitoring and counseling. These are indeed two serious concerns, but the jury is still out on whether the proposed solutions will resolve the issues sufficiently. In the meantime, allowing PGD to go forward constitutes experimentation on children that many find unacceptable. Even if we can resolve these two concerns, other key ethical problems remain.

3) Still others claim that “the public” “supports” the process. Such language seems to suggest virtual unanimity. However, the opinion poll cited in May news reports actually shows the U.S. public divided, with only 60% in favor of the procedure. Furthermore, some countries such as Germany and Italy ban the practice entirely. Regardless, 60% support does not make a process right. If it did, then ethics is nothing more than a determination by the majority's opinion without respect for fundamental truths and rights.

Using PGD as a method of weeding out undesirable offspring is unethical by its very nature. “Savior babies” are just the latest (and perhaps clearest) example of how utilitarian thinking can be demeaning to human beings. Whatever the variation, the basic approach of PGD involves producing many more human beings than are wanted, selecting those deemed best, and discarding the rest.

Most often, the goal is to avoid passing on a genetic disease, though PGD is sometimes used for gender selection or selecting children with other traits as well. Using PGD to avoid having a “diseased baby” is a classic example of identifying a serious human problem and rushing to address it with the most easily accessible method available rather than with a truly ethical technology. Identifying serious problems such as genetic diseases is praiseworthy, and being strongly motivated to avoid them is even more

laudable. However, allowing human beings to live only if they “measure up” genetically represents a profound shift in what it means to be a human being. It suggests that some human beings do not have enough value to justify their existence.

Children produced through this technology are received into the world—into a family—only because they do not have some unwanted problem. Their lives would have been terminated if they didn’t measure up to being “normal.” The demise of unconditional acceptance and love that usually exists when a parent has a child, whether they are healthy or not, does not bode well for the inevitable situations when other unwanted problems arise in a child’s life.

It also doesn’t bode well for those in our communities who are disabled. After all, if my child wasn’t worth saving because of health or disability, why should we tolerate others who intentionally allow a disabled child to be born? Why should we pay for the care necessary to ensure they have as good of a life as they possibly can?

Embryos are entire beings, not merely cells, and human embryos are, accordingly, human beings. Does every innocent human being have a God-given dignity that warrants respect and protection? Selective PGD says no.

But many people disagree. Some argue that on the scientific basis of genetics, embryos are protectable because they are beings with a full human genetic code. Others would similarly protect human embryos on the biblical basis (Genesis 1) that the image of God is present in living beings who are human as opposed to animal, etc. Still others would protect embryonic humans simply because their status is debatable and uncertain. Just as we take special precautions not to engage in behavior that might harm human beings, they observe, so we should not engage in behavior harmful to those who might be human beings.

Every dollar spent on PGD to identify which embryonic human beings to discard—rather than on developing ethical ways of preventing and curing genetic diseases—is a shame. Compassion for sick children and their families demands a better approach.

Can PGD play any ethical role in a better approach? If so, it would have to involve using it for the good of those tested, rather than employing it to their detriment.

For example, if the purpose is to identify genetic problems in order to prepare for any special supports that will be needed later, then the intention is admirable. However, it is better to avoid the ethical problems associated with producing embryos in the lab, especially if the mother can become pregnant without the use of assisted reproductive technologies. In any case, if future support is the intention, then diagnostic tests other than PGD can be done during the pregnancy to identify genetic problems (although the risks of any diagnostic test must be sufficiently known and limited in order to justify using it to obtain the desired information).

Similarly, if the purpose is to use genetic therapy to correct problems identified through PGD, then the intention is also admirable. But, genetic therapy to correct problems is so undeveloped at the moment that PGD can do little to assist it. Even with developments in genetic therapy, PGD would not be necessary if the therapy can take place later than the embryonic stage, or before conception (with the benefit that the genetic error is corrected in all cells of the body).

Thus the use of PGD would be ethical in a situation where the use of assisted reproduction technologies is necessary and a genetic therapy is available that must be done at the embryonic stage. But such is never the case today—and some say it may never be.

Then preimplantation genetic diagnosis appears to have a poor prognosis indeed. **CBHD**

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