Designer Genes: When Having a Child to Save a Child Causes Some Children to Die

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Why did the Human Fertilisation and Embryology Authority (HFEA) recently refuse Jayson and Michelle Whitaker permission to create a "designer baby" who could serve as a tissue match for their three-year-old son suffering from a rare blood disorder called Diamond-Blackfan anaemia? In December of last year, the authority allowed Raj and Shahana Hashmi to create a baby by in vitro fertilization (IVF) and then undergo pre-implantation genetic diagnosis (PGD) and tissue typing to serve as a donor for their son suffering from thalassaemia. What is the difference between these two cases?

According to the HFEA, Human Leukocyte Antigen tissue typing (HLA) "may only take place when pre-implantation genetic diagnosis is required to avoid a serious genetic disorder." In the case of the Whitakers, their son's condition is thought to be the result of a sporadic mutation. Hence, they are not believed to be at risk of having another affected child and are therefore not eligible for PGD.

By contrast, the Hashmi couple were granted permission to undergo PGD precisely because they were at risk of passing on thalassaemia, a serious genetic condition. It was only because they were allowed to use PGD that they were allowed also to use HLA to select embryos (free from thalassaemia) that were tissue compatible with the existing affected sibling.

Needless to say, it is terribly tragic when a family is at risk of losing a child affected by a serious health condition. However, is it ethical to create a child specifically for the purpose of saving the life of another? Obviously, parents in such a situation may argue that they would want a second child anyway. Nevertheless, the question remains whether a child should not be wanted solely for its own sake and welcomed unconditionally. Aren't we all created in the image of God and therefore equal before God? Is PGD itself justified? And if so, is HLA justified as a further means
of "weeding out" (destroying) nascent human life?

It is important to recognize what many people do not--that the very intent of PGD is to allow for selection against some embryos. That is to say, embryos who are found to be "defective" are discarded or used for research in which they are ultimately destroyed. PGD in connection with IVF entails the deliberate creation of embryos followed by the deliberate destruction of those determined to have a genetic disorder. It involves the intentional destruction of nascent human life and is therefore contrary to the principle of the sanctity of human life. It cannot be disputed that the embryo is human and is a human. To destroy an embryo is to cut short a human life that has already begun.

The HFEA is now being challenged in the courts by CORE (Comment on Reproductive Technology), which has been granted a judicial review of the HFEA's ruling in the Hashmi case. In other words, CORE is challenging the HFEA's decision to allow HLA in connection with PGD for the purpose of choosing suitable donors for the treatment of existing siblings. CORE is challenging the very principle of selecting children on the basis of whether they are able to serve as tissue donors--rather than the individual Hashmi decision. The date for the judicial review has not yet been set.

As noted earlier, the combination of IVF and PGD involves the creation of several embryos and the selection of embryos shown not to have a particular genetic disorder; embryos who do have the disorder are destroyed. HLA tissue typing involves further screening to select an embryo or embryos whose tissue is compatible with an existing sibling who suffers from the disorder. If a suitable donor embryo is found, he or she is implanted in the mother. After the child's birth, stem cells are harvested from the umbilical cord and transferred to the affected child in the hope of saving his or her life. According to the HFEA, "the intention should be to take only cord blood for purposes of treatment." However, if this procedure fails, what guarantee is there that bone marrow will not be taken from the infant in order to cure the affected sibling? This would raise further ethical problems, given the medical risk (entailed in all invasive procedures requiring anesthesia) involved for the donor (who would be unable to provide consent).

It is noteworthy that in November 2001 the joint working party of the HFEA and the Human Genetics Commission, in light of the responses to a consultation paper, declared that prenatal diagnosis combined with tissue typing to select donors should under no circumstances be allowed, since such testing raised "ethical difficulties." It appears that the HFEA has now changed its mind.

One may ask whether the HFEA should even have the authority to decide matters such as this. On July 18th, the House of Commons Science and Technology Committee (STC) published a report that was highly critical of the HFEA. The authority was criticized not only for its inefficiency, but also for overstepping its bounds by making decisions that ought to be made by Parliament. In other words, the STC suggested that it would be more appropriate for Parliament, as a representative of the British people, to decide whether or not it should be permissible to create and select embryos with a view to finding suitable tissue donors for existing children. This assertion was made on the grounds that the HFEA cannot speak for the British people. It has no mandate to do so since it is not an elected body. It was pointed out that, when asked about the decision to allow the Hashmis to create a "designer baby" to serve as donor for an existing
sibling, Dame Ruth Deech declared that the public had been consulted about PGD. Deech's statement was correct; however, as observed by the STC, the HFEA's consultation "did not address the issue of tissue typing to benefit an existing family member."

The SCT has recommended a revision of the 1990 Human Fertilisation and Embryology Act, which established the HFEA. Both the integrity and the competence of the HFEA have been put in doubt. Science has advanced considerably in the past 12 years and, according to the SCT, it is time to bring the Act up to date. What is needed is an authority consisting of representatives not only from the liberal utilitarian camp (as is presently the case) but also of representatives with religious and pro-life convictions. Such a change is much needed and would be most welcome.

Finally, the public should be told the full truth about PGD and tissue typing. They should be told that PGD involves the deliberate creation and destruction of human life. They should be told that tissue typing may require the creation of many embryos--healthy and unhealthy--before a single one is found that can be used as a donor for an afflicted sibling. The Hashmis have yet to succeed in creating an embryo that is tissue compatible with their ill son. A number of their healthy embryos have been stored for an uncertain fate, while unhealthy ones have been discarded. What is at stake in the pursuit to prolong life is the deliberate wastage of other human lives.

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