

A Closer Look at Preimplantation Genetic Diagnosis (PGD)

New Technology Brings New Pressures on Families

Preimplantation genetic diagnosis (PGD) was initially developed to detect inherited serious genetic disorders—often those fatal in early childhood. For families who have already lost a child to such a disease, or who may be struggling to care for a child with such a disease, PGD can offer hope for the future.

Increasingly, however, PGD is being used as an adjunct to standard IVF by couples with no family history of serious disease, but who are struggling with infertility. In this context, PGD is used to detect abnormalities in chromosome number, called *aneuploidy*, which can interfere with successful IVF and pregnancy. Although the data showing PGD's effectiveness in this context is limited, some IVF providers recommend PGD to infertile patients over 35 or those with repeated IVF failure. Other providers have suggested that eventually, PGD will be offered to every patient. Since over 1% of all U.S. newborns are IVF babies, aneuploidy screening accounts for the biggest growth area in the use of PGD.

PGD creates a number of new issues for families and family therapists. Couples considering the use of PGD face considerable financial and emotional pressures. It adds thousands of dollars to the already substantial cost of IVF, and many prospective parents go deeply into debt. Further, given the limited data available about PGD's effectiveness, prospective parents may struggle to understand whether PGD will improve their chances for success.

Regardless of cost, some parents put pressure on themselves to find a way to afford PGD. They may believe that it will maximize their chances of becoming pregnant, or that PGD will allow them to select the "healthiest" embryo, giving their child the best chance at a healthy start in life. The additional choice of PGD added to the technology menu may bring considerable added stress.

More controversial applications of PGD include its use to select an embryo that is an immunological match for a sick sibling; to select the sex of an embryo in the absence of a sex-linked disease risk; to test embryos for gene mutations associated with diseases such as early-onset Alzheimer's disease or Huntington disease that do not appear until later in life; or to test for mutations that indicate a heightened, but uncertain risk of developing a particular disease such as cancer.

Some observers believe PGD, by allowing parents increased control over the genetic makeup of their children, has the potential to fundamentally alter family dynamics. Human reproduction could come to be seen as the province of technology. Such a shift, if it occurs in large enough numbers, could affect both prospective parents and their future children by changing the expectations of everyone involved.

Some parents may view PGD as merely the latest version of

giving their child every possible advantage—a pre-pregnancy version of private nursery school or swimming lessons. Yet the knowledge that such technology was used could put pressure on a child to live up to the expectations that he or she be "perfect" in some way. The future implications are uncertain: several years down the road, will an adult child who develops a genetic disease resent the parents who did not use PGD to detect that mutation? Or will children born after PGD resent knowing so much about their genetic makeup from birth?

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It remains to be seen to what extent PGD may affect family dynamics. A study has been approved at Baylor College of Medicine in Houston to study the impact of allowing prospective parents to use PGD for sex selection. Yet approval of that single study took nine years, and the data that it provides will be a small piece of the puzzle of what the impact of PGD might be. For the future, The Genetics and Public Policy Center, in conjunction with IVF and PGD providers, has begun to design a voluntary, national database that will allow future research on the impact of PGD. PGD is an important new option for prospective parents, but the issues it brings to families and family therapy clearly are still emerging.

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