Ethics and Reproductive Genetic Testing: The Need to Understand the Parent-Child Relationship

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Reproductive genetic testing raises complex and perplexing ethical issues. Why is this so? In significant part, the reason is that the dilemmas posed by reproductive genetic testing implicate the parent-child relationship. Ethics and law lack an adequate theoretical basis for understanding the structure and functioning of the family—especially the parent-child relationship. Therefore, those who wish to resolve ethical issues in reproductive genetic testing are seriously hindered.

It is particularly difficult to conceptualize the duties and obligations that should revolve around the parent-child relationship. The two parties are not strangers; thus, it would be inappropriate to assume that they will be motivated primarily by self-interest. Conceptualizing this relationship is further complicated by the fact that the parties involved are not of equivalent status: the fetus is always dependent and vulnerable.

The parent-child relationship is linked to an understanding of women's biological and social roles. Only women gestate. In addition, childrearing has been and continues to be the overwhelming responsibility of women. Although men are biological parents and are responsible for the care of children, the parenting role is not culturally understood to be a defining one for them.

The most perplexing aspects of the parent-child relationship involve the decision of whether, and under what conditions, a
pregnancy should be initiated, and if so, what the appropriate
treatment of the fetus should be. These issues go to the heart of
the ethical and policy-making questions raised by reproductive
genetic testing. Moreover, to a large degree it has been the
advances in genetic and reproductive technologies that have
highlighted the lack of a sufficient theoretical account of the
parent-child relationship. The need for an adequate analytical
framework will assume even greater urgency as current efforts
to map and sequence the human genome progress.

Genetic and reproductive technologies have increased the
power of individuals (and couples) to decide whether to procre­
ate and whether to control the size, timing, and desirable char­
acteristics of offspring. Not only have those advances opened
up new possibilities for individual reproductive choice, they
have also provided governments and private institutions with
more efficient methods of coercing reproductive choices. For
example, both governments and private institutions can refuse
to pay medical costs incurred by a child who was prenatally
diagnosed as having a genetic disease but not aborted.

To make matters more complex, increased options for indi­
viduals, private institutions, and the state have become available
at the same time that the family itself is undergoing profound
change. The elevated status of women and children within the
traditional family is changing the roles of family members
and the nature of interactions among them, while the growth
of single-parent families is a stark reminder of the reality that
women and children increasingly live in nontraditional envi­
ronments.

In short, guidance for private and public policy decisions in
reproductive genetic testing is urgently needed, yet difficult to
provide. Below I will identify the areas implicated by the parent­
child relationship that I believe are most in need of attention if
we are to make progress in resolving the dilemmas posed by
reproductive genetics.

The critical issue at hand is the need for an understanding of
the parent-child relationship, including the period of preg­
nancy, that is grounded in the experiences of parents in their
relationships with offspring. I agree with those who argue that
a "language shift" is needed. A language shift is undeniably
linked with the need for a different conceptual framework. Terms and concepts such as choice, autonomy, rights, and non-interference, do not capture my own experiential understanding of pregnancy or of parenting after birth, nor do they capture what I can remember of my experiences as a child.

These terms and concepts seem especially problematic in the context of my experience of pregnancy. Pregnancy is typically described from the perspective of either the woman and her rights, or the fetus and its rights. Such descriptions tend to oversimplify matters. In my experience, a woman who wants to have a child sees herself as involved in a relationship with the fetus—a relationship that is not adversarial or antagonistic. The fetus is both a part of a woman's body and a separate, distinct entity that may suffer injury not suffered by the woman. A woman's experience of pregnancy is thus complex, informed with multiple meanings, not fully captured by language that emphasizes separateness and rights.

Moreover, a woman does not exist with her fetus or child in isolation; she may have relationships with other children, a spouse, family members, or significant others. Decisions that she makes with respect to any one of those relationships must take into account her involvement with all of the others. There needs to be a way to include the contextual nature of a woman's decision-making. I am not sure what the language or concepts should be—obligation, duty, responsibility, care, love, compassion?—but there is a clear need to move away from the existing language and its conceptual implications. In short, we need a different analytical approach that focuses on relationships where one party is dependent and vulnerable.

Whatever form a revised framework takes, it should contain a broad and inclusive understanding of who a parent is and what it means to parent—again, an understanding anchored in the experiences of parenting. An ongoing problem has been that reproduction has primarily been associated with women. Yet there is no reason why male responsibilities should not also be addressed. One of the implications of using terms such as responsibility, obligation, and care is that they are not limited in their applicability to women. These terms serve as reminders that men are also parents. From my perspective as parent, wife,
and former child, involving men in parenting responsibilities serves only to benefit us all.

What must parenting entail? Often parenting is discussed as though it requires total sacrifice of the parents' interests. While many parents may indeed strive for sainthood, parenting cannot require such complete sacrifice in the name of the best interests of the child any more than it permits utterly self-interested behavior. A balance needs to be struck. Too much self-interest is detrimental to children. However, requiring total sacrifice of parental interests would be burdensome, and persons would choose other ways of occupying their time. Moreover, parents must sometimes consider the needs of others. Parenting a child does not exist in isolation from the needs of other children, dependent persons, or even of spouses and friends.

A better understanding of what it means to parent raises the possibility that acting responsibly may encompass a decision not to parent. This is not an idea that has received sufficient attention; it arises quite naturally, however, in the context of genetics and prenatal diagnosis of disease. Let me hasten to add that I absolutely agree with the view expressed by several authors that the decision to terminate a pregnancy after prenatal diagnosis of a genetic disease cannot be justified as being in the fetus's best interests. A decision to terminate a pregnancy might nonetheless be a responsible decision in view of the needs and life circumstances of the pregnant woman and those affected by her decisions. I was recently told the story of one pregnant woman with an existing child who recounted that she really didn't agree with abortion, but believed she must have one because she felt she should focus on the needs of the child she already had. A new child would mean that her existing child would not receive all of the attention it needed. The view expressed by that woman may be difficult for some to understand, but given certain circumstances, it makes a great deal of sense to me.

Finally, in thinking about what parenting might entail, we need to keep in mind that women come from many cultures, ethnic groups, and economic classes. Our ethics therefore should be contextual not abstract in nature. It must take into account the infinite varieties of family life and relationships. My
family law students are given to saying, "a reasonable mother would . . . " They are reassured by the notion that there can be some high degree of objectivity in describing the role of parents. I prefer to emphasize what a reasonable parent would do under the circumstances—an emphasis that draws attention to the problem of generalization. I also stress the difficulty of outsiders' truly being able to appreciate all of the circumstances in others' lives.

Shifting to different paradigms, however, is not risk-free. We live in a society that wants to make ethical requirements legal ones—to compel behavior to conform to objective norms. Thus, prevailing norms of parental responsibility become forces that shape when, how, and with whom the state should intervene. For example, a "strong" view of parental obligation has often implied that the state should help only when parental resources are exhausted or otherwise unavailable. When the state in its role as provider of last resort supplies resources, moreover, it does so only to help the weak, vulnerable, or dependent individual as opposed to the family unit or the parent. A "strong" view of family obligation may also be used to justify punishment of family members who are perceived as not meeting parental obligations. As a consequence, many fear, with good cause, that a focus on parental obligation rather than on rights is an invitation to greater interference by the state into the lives of individual parents than is desirable.

We must not forget that technological innovations have the potential to vastly expand parental options about reproduction and the characteristics of offspring. Economic, social, and demographic changes have the potential to continue to alter our traditional understanding of the family, its structure, and inherent responsibilities. Significant changes in social expectations about parenting may result. This is particularly a problem in genetics. The President's Commission in 1983 warned of this possibility in the context of prenatal therapy. It stated:

If the capacity to perform prenatal therapy expands, significant changes are likely to occur in social expectations about parental and societal obligations to the unborn. . . . One aspect of this change would be more demanding so-
cial expectations of parents in promoting the welfare of the fetus. So although the developments in prenatal therapy increase the range of technically feasible options, social pressures may severely limit parents' freedom to refrain from choosing certain options.¹

In the context of reproductive genetic testing, there could be increased pressure to reduce the degree of choice permitted in these decisions, in the interest of the collective goal to reduce the incidence of genetic disease.

Related is the concern that state involvement in individual reproductive decision-making will not fall equally across the population. The vulnerable—women, minorities, and the poor—will bear the greatest burdens, as historical evidence corroborates. Women, in particular, fear that a conceptual framework focusing on responsibility, obligation, and care too closely resembles earlier definitions of women's roles that served to oppress and disadvantage women in relation to men.

Those risks are real, and current frameworks have proven inadequate. Risks can be ameliorated, however, by taking into account several factors: First, the ability to protect bodily integrity—especially the body's reproductive functions—is critical to self-identity and should not lightly be ignored. Second, while legal regulation of the parent-child relationship might be appropriate in some situations, it is difficult, if not impossible, for law to require all of the endless care and kindnesses toward others that we associate with intimate, and sometimes dependent, relationships. Third, historically, ethics and law have permitted a broad range of parenting behaviors. We should move away from this perspective only with the greatest of caution. Finally, and perhaps of the greatest importance, many parents are willing to act in the interests of their children, but may not have the training, resources, knowledge, skills, or fortitude to act without support from others (including the state) to carry out their responsibilities.

A revised framework for understanding the parent-child relationship must therefore include a basis for protecting the privacy traditionally associated with parental decision-making without unduly exposing vulnerable persons to harm. At the
same time, this framework must recognize that no families are alike and that some require affirmative assistance rather than punishment in order to meet their own expectations and the expectations of society as a whole.

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