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Essay

GENETIC NARRATIVES:
BIOLOGY, STORIES, AND THE
DEFINITION OF THE
FAMILY

James Lindemann Nelson, Ph.D.†

That biomedicine's power puts pressure on the idea of "family" is neither a novel nor a particularly arcane notion.¹ Still, despite the attention already directed to the subject, there are aspects of the interconnections between families and biomedicine which demand continued exploration. In this essay I seek to clarify the role of genetic connection in our understanding of what is valuable about family life.

The significance of "blood ties" is both highlighted and made problematic by medicine's "new reproductive technologies," a large assortment of ways in which physicians encourage reluctant eggs and sperms to get together. Gamete donation and "surrogate motherhood" are dramatic examples of medically mediated reproductive interventions which raise questions about the importance of biological connection, but the expense, invasiveness, and low success rates of many forms of assisted reproduction testify to what many of us are willing to go through in order to have children of "our own"—that is, children with whom we share our genes.

More distantly but perhaps more profoundly, the importance of biology and biological connectedness is reflected in the view of the significance of genetics that at once nurtures and is nurtured by the Human Genome Initiative. This latest example of federally sponsored "Big Science" endeavors to locate the position of human genes on the chromosomes. It also attempts to identify the order of


the chemical sub-units of DNA in any segment of a gene. The billions of dollars earmarked for this project eloquently testify to the importance we place on genetics.\(^2\) We look to it for a deep understanding, not only of diseases such as Huntington chorea, or cystic fibrosis, but an understanding of ourselves. Progressively, who we are is being seen in terms of what genes we have and how they express themselves.

In order to get a finer sense of what it is we find so important at the level of biology, I will contrast the account of familial ties which gives pride of place to genetics with an account that stresses social interactions—an instance of the enduring "nature-nurture" debate—and conclude by developing an idea suggested by work of William Ruddick: that the real significance of genetic ties is best seen by their contribution to the richness of the ongoing familial narrative in which our individual lives are enmeshed.\(^3\)

A DISCURSIVE PRELUDE

The new reproductive technologies and practices are, for the most part, unexceptionable from the perspective of a liberal polity. Informed consent and explicit contracts abound, and if there are problems with our current forms and contracts, reformist measures would seem to meet the case—just provide better information, make the contracts explicit, and hedge it all round with plenty of consumer safeguards.\(^4\) But we are not altogether comfortable with these new ways of bringing children into the world, and tinkering with the details does not seem to assuage our concern. Surrogate-ship contracts, for example, are quite widely regarded as "unenforceable as contrary to public policy."\(^5\) Some of this concern likely


\(^3\) I make very free with this idea, so expressing my indebtedness to Ruddick for germinating my thinking about it should not be interpreted as attributing to him details, implications, or even the language in which I express the notion. I take the basic thought from the remarks made by William Ruddick in discussion of his paper, Ethics for Kith and Kin, presented at the Hastings Center meeting on the Family and Bioethics, March 7, 1991 (paper on file at the Hastings Center).


\(^5\) In its report of state laws on surrogate motherhood, the American Fertility Society reports that surrogacy is banned in Arizona, Kentucky, Louisiana, Nebraska, Maryland, Michigan, Utah, Washington, and North Dakota (American Fertility Society State Legislation Fact Sheet, 1990). Legislation to regulate surrogate contracts is currently being considered in California; the legislation distinguishes between genetic surrogates and gestational surrogates who have no genetic link with the baby. Genetic surrogates would be allowed to
stems from a conviction that such technologies threaten to exploit the vulnerable in ways not easily regulated, or that they will reinforce distortions in our culture's conception of the significance of women. For example, consider "contract gestation," in which a woman harbors and bears a child which grows from another woman's fertilized ovum. While this form of technologically mediated reproduction has had results which seem heartwarming (as well as confusing) as in those celebrated cases in which women have gestated their own grandchildren for infertile daughters, it also raises more sinister specters of the exploitation of poor women as living incubators of the children of privileged couples.

But much of our residual hesitation over these new techniques seems to reflect an allergy to medicalized reproduction's impact on concepts and relationships that lie close to the heart of how we understand and value families. A quick survey of images and attitudes evoked by reproductive technologies supports this suggestion. Surrogate motherhood has conjured up the image of baby selling and suggests uncomfortable analogies between motherhood and prostitution. Ovum donation, in which a woman provides a gamete to be fertilized and gestated by a couple of which she is not a part, threatens to make maternal identity as potentially ambiguous as paternal identity.

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8. The analogy between prostitution and surrogacy is suggested in Richard T. Hull, Ethical Issues in the New Reproductive Technologies (1990) at 153: The author suggests that "... contracting for the use of one's uterus is perilously close to contracting for the use of one's vagina; the parallel with prostitution strikes many as compelling and all but one of the states prohibit prostitution contracts."

9. It is worth noting that artificial insemination by donor, the male analogue of ovum donation, has not occasioned similar concern; we seem rather more relaxed, as a society if not always personally, about paternal ambiguities. See James L. Nelson, Parental Obligations and the Ethics of Surrogacy: A Causal Perspective, 5 PUB. AFFAIRS Q. 49 (Jan., 1991). It is also worth noting that the assumption of the incorrigibility of maternity obscures the issues involved in adoption, and thus could be seen as loading the question in favor of biology over nurture in determining what's essential about parenthood.

Ironically, contract gestation and ovum donation (or vending) make motherhood ambigu-
At the same time, albeit somewhat less vividly, biomedicine's growing interest in the human genome also sparks some concern about why and how family ties are an important matter. The focus on the genome as the key to unlocking human reality may undergird the tendency to construe human identity and fundamental relationships in terms of the biological links of genetics, rather than the social ties of nurturance, or other biological connections, such as gestation. This sort of thing has, at least in some corners of popular imagination, put medicine into company with more familiar "threats" to the family such as television and mothers who work outside the home. Among scholars, it has incited calls for new laws to clarify the family relationships that biomedicine has obscured. In (at least partial) contrast, I view these developments as an opportunity to refine our understanding of what is important about families. While such exploration may contribute to determining just what new public policies might be most defensible, delineating policy will not be my goal. I will particularly worry over the question posed quite vividly by juxtaposing contract pregnancy and gamete donation: ought genetic connections be privileged over other forms of human connectedness in our understanding of family life?

By way of stage setting, I begin with some remarks about a pair of useful, although somewhat unstable distinctions: instrumental versus transformative power, and regulative versus reflective bioethics.
Our power is typically directed toward securing ends that we value. For example, we strongly tend to value being free of any nontrivial amount of pain, and so we develop a whole raft of technologies designed to achieve this end. These exemplify what I will call instrumental power. We can also use our power in a different way: not to achieve ends, but to change them. Bryan G. Norton provides a vivid example of how this works: a teenager whose musical tastes are fixed on rock unwillingly attends a classical concert to avoid offending her grandparents. Much to her amazement, she finds that live classical music is thrilling; without abandoning rock, she now includes classical music in her listening and in her music purchases. Norton speaks of the concert as exemplifying transformative value; an object has transformative value if it provides an “occasion for examining or altering a felt preference rather than simply satisfying it.” But we might also focus on how her grandparents used their influence to alter their granddaughter’s ends, and speak of transformative power.

As I have already acknowledged, this is an unstable distinction: some exercises of power will have both instrumental and transformative elements. Sometimes transformative power will be used in an instrumental way, as when someone wishes to change his culinary tastes in order that he may lose weight. Further, transformative power, although it has a dramatic ring to it, can be a fairly homely phenomenon, as in the case that Norton cites. Still, power to transform structures that are deeply involved in the formation of our identities, and hence in the formation of our preferences, values, and ends, is more and more a part of biomedicine, and, as I will argue, particularly of those parts of biomedicine which affect families. On its face, such power deserves careful attention.

BIOETHICS

The interdisciplinary field of bioethics is our culture’s response to this need for careful attention. It has attained a certain kind of social significance as a regulative discourse, one that provides us with the means of deliberating how to direct, control, and distribute the power of contemporary biomedicine. But its deeper significance

16. Id. at 10.
resides in its role as a reflective discourse, a meditation on the impact of biomedical power on fundamental concepts that shape our understanding of the world and guide our action in it—e.g., life, death, freedom, aging, family. This distinction shadows that between instrumental and transformative power, and is subject to the same kinds of messiness about the edges.

The genome project is a prime example of how biomedical power portends important changes in the meaning of our lives. It is potentially the most powerful example of how biological accomplishment and application may alter human reality, immediately giving rise to clouds of "regulatory" kinds of questions: how do we maintain confidentiality of information pertaining to a person's genetic weaknesses? How do we prevent adverse consequences in terms of employability and insurability? How should we set priorities here, as we focus our resources on understanding one genetic disease rather than another? How do we deal with the psychological implications of the fact that, given a particular genetic disease such as, say, Huntington chorea, diagnostic ability will precede therapeutic ability by several years?

But the deeper, "reflective" questions are there as well: are there any limits on the extent to which we ought to alter our genetic composition? Will we have to give up our sense of ourselves as free and responsible beings, whose fate is, to some extent, in our own hands? And, for present purposes, a more concrete question: should our growing understanding of the role of genetics in human life have an impact on the meaning we attribute to an important way in which genes are passed on in our species—through marriages and the institution of the family?

FOCUS: FAMILIES AND THE IMPACT OF BIOMEDICAL POWER

It is, I venture, a measure of the importance of families to our lives that virtually any discussion of the topic must include some explicit discussion of what is meant by "family," a requirement enforced much less vigorously when other complex and significant ideas are on the table. However, writers have offered reasons for suspicion about discussions of the moral significance of the family which are not accompanied by articulated and defended definition—most typically that the family today takes on such a bewildering-

17. For the distinction between regulatory and reflective bioethics, I am indebted to Daniel Callahan (in conversation).
ing variety of forms that any assertions regarding it must be carefully qualified. But rather than attempt a rigorous definition in descriptive terms (e.g., "a group of individuals living under one roof and usually under one head," or "the basic unit in society having as its nucleus two or more adults living together and cooperating in the care and rearing of their own or adopted children") my approach is normative. Starting with clear paradigm cases of families, I ask, in effect, "Is there anything of special moral significance happening in these groups? Are the characteristic forms of relationship here especially bound up with goods which we appropriately value highly, and which are not likely to be obtained elsewhere?" If we can discern any interesting positive answers to these questions, then we can use the presence of such features as the basis of our definition of family as a morally significant notion. In other words, any social arrangement which incorporates these special goods, or at least most of them, will count as a family for present purposes. While this is not an altogether rigorous approach to definition, it certainly has enough precision to get along with.

What special goods, then, do families contain and convey? An important answer seems to lie along these lines: families, whatever their particular configurations and bedeviling moral weaknesses, endure, and ought to endure, because they are among the most important mechanisms through which we form and sustain selves. Families are significant contexts in which we enjoy intimate relationships, places in which we can express parts of ourselves which we elsewhere suppress, places where we can know and be known with a sort of particularity that doesn’t often occur elsewhere. This does not mean that they are the only places where this kind of work goes on, or even that they are the best places for it. But despite these disclaimers, the tasks they undertake are deeply significant. Further, families are important in an “outward” directed way as well; they are the basis of our training in sociality, of our ability

18. Fred Rosner, 2 J. CLINICAL ETHICS 87 (Fall, 1991).
20. The danger with this approach is that it tends to obscure whatever may be going on in “marginal” families which is of distinctive moral significance. For example, families constituted by lesbian parents may be making important contributions to social justice, by undermining misogynistic assumptions that are prevalent in many other forms of social life. However, if we see the paradigm case approach as one form of analysis of the moral significance of families, to be supplemented by others—particularly others focusing on the importance of difference, as well as of resemblance—this danger may be lessened.
to respond to others as people with ends of their own, quite possibly distinct from our own ends.\textsuperscript{22}

Having sketched out why families are important, the question becomes whether biomedicine is exerting transformative power on the family, i.e., power that will alter not simply how it goes about obtaining its ends, but those ends themselves. The power of biomedicine is exerted both through biology, and through the social practices and structures in which its biological insights are put to use. To understand and assess its impact on the family, we need to sort out the contribution of biology, on the one hand, and culture, on the other, to what it is that makes families important.

Focusing on the role of families in forming and maintaining selves might seem to suggest that social relations—the nurturing ties through which individuals become acculturated—are of primary significance in understanding what is important about families. There is, however, a great deal of evidence that suggests that genetic ties are of immense importance to family life. The experience of many adopted children is on point here; researchers report a consensus in the literature that adoptees are more vulnerable than nonadoptees to "identity problems developing in adolescence and young adulthood,"\textsuperscript{23} and anecdotes abound concerning the search of children raised in loving, nurturing adoptive homes, for the birthparents whom they have never seen.\textsuperscript{24}

From the perspective that sees the essential moral tasks of families as forming, nurturing, and maintaining selves, this seems rather curious. Why should people seek out those who have merely a physical relationship with them, think of them as somehow linked to them as parents, when they have been the recipients of prolonged and intense caring, day after day, year after year? Why isn't it enough to be intimately involved with those who have been so deeply engaged in shaping one's loves, values, preferences, and life plans?

Consider this possibility: our genetic ties are extremely important to us. Our genes determine, to an important extent, our identities as persons. The genome project is telling us more and more about this, but we have really known it all along. And this is part of

\textsuperscript{22.} LAURA PURDY, \textit{IN THEIR BEST INTERESTS?} (1992).
\textsuperscript{24.} For discussions of the prevalence and significance of such searches, see MICHAEL HUMPHREY & HEATHER HUMPHREY, \textit{FAMILIES WITH A DIFFERENCE: VARIETIES OF SURROGATE PARENTHOOD} (1988).
the key to understanding both the significance and the form of the family: ideally, it is an association which is based in nature, not in contrivance or artifice. While our sociability in other contexts may indeed be said to be natural, it is not as deep or fixed as the intimate relationships that are grounded in genetic connection—contrast, for example, the prevalence of divorce, which sets aside a contractual relationship, with the rarity of "disowning" one's children.

Families founded on, or expanded by, surrogate motherhood or gamete donation are families which are founded (at least in part) on artifice, not (wholly) on nature. The contingency of human life makes it inescapable that some parents will die before their children are raised, or that they will not be in a position to raise their children after their birth. Therefore, some families must be constituted or augmented by artifice. But these families represent a compromise with necessity, and inherit a good deal of problematic baggage. On the other hand, if we explicitly engineer situations in which families rest on artifact rather than nature, then we are setting out for our own purposes to put children in situations in which they will not enjoy intimate contact with their genetic relations. The consequences of this can only be guessed, but our difficulties with adoption provide significant hints.25

There is, of course, another view of all this, from which human beings and their relationships are seen as more or less independent of biology. What's most important from this perspective is our status as autonomous agents, and the most fundamental kind of moral relationship is, then, the contract, a form of interaction which patterns human interaction from the most formal to the most intimate. Marriages are clearly contractual, but we can even view the process of "starting a family" as volitional and at least quasi contractual. A couple—or an individual, for that matter—decides to start a family, or augment one. They consider their options. Many people are in a position to become part of a "pregnant couple"; some are not, and must exercise other options. But even those who can become pregnant sometimes avail themselves of other options, and even after

25. See Paul M. Brinich, Some Potential Effects of Adoption on Self and Object Representations in THE PSYCHOANALYTIC STUDY OF THE CHILD 107 (Albert J. Solnit et al. eds., 1980); Paul M. Brinich & Evelin B. Brinich, Adoption and Adaptation, 170 J. NERVOUS & MENTAL DISEASE 489 (1982). These authors suggest that adoption is "always painful and potentially traumatic" because of its involvement in two significant "social failures": first, that the child is unwanted; second, that the adoptive parents are unable to conceive. Brinich and Brinich conclude that the "psychopathological potential" of these failures is great. See also Katharine Davis Fishman, Problem Adoptions, THE ATLANTIC MONTHLY, Sept. 1992, at 37.
pregnancy commences, there are still choice points: a pregnant woman, at least if she possesses sufficient economic resource, can decide whether she wants to go through with the pregnancy. And then, even after the baby is born, the parents can decide whether or not to nurture her or him as parents. Sara Ruddick likens this decision on the part of the biological parents to the decision to adopt a child on the part of nonbiological parents—every child is adopted, on this scenario.26

While it is true that many children who are adopted out of their genetic families later wish to make contact with them, and that some are distressed if they can't, that surely is more plausibly attributed to a certain kind of socialization, a certain romanticization of the family, rather than to some altogether obscure idea of "genes calling to genes" directly. As a response to the point pressed earlier about the rarity of disowning children contrasting with the ubiquity of divorce, consider the tendency for men who are not integrated into a functioning, social family, to abandon or much attenuate their relationship to their children.27 Fathers are as genetically related to their kids as are mothers; isn't it very plausible that male patterns of socialization, with their emphasis on separation and individuality, are involved in the explanation for this phenomenon?28

GENETIC NARRATIVES

Two images of why families are important have been presented here. The first, which might be called the "natural kind" view of families, emphasizes the rooting of familial relationships in biological processes which, while surely affected by social constructs, in some sense underlie social constructs, make them possible, and are more fundamental. This view seems to accommodate some significant data about family relationships—our persistence in seeking out genetic ties, our increasing technological ingenuity in learning how to establish them—but seems unable to handle other data, male abandonment of children, for example. Further, the mechanism

26. "To adopt is to commit oneself to protecting, nurturing and training particular children. Even the most passionately loving birthgiver engages in a social, adoptive act when she commits herself to sustain an infant in the world." SARA RUDDICK, MATERIAL THINKING 51 (1989).

27. For a compendium of relevant data, see SUSAN OKIN, JUSTICE, GENDER AND THE FAMILY 134-69 (1989).

through which all this happens seems obscure. Are we supposed to posit some kind of brutally biological urge here?

The second, "social artifact" view of the family has the great strength of seeming to accord more closely with how it is that families do their most morally significant work: forging and maintaining human selves, not simply human bodies. It also seems able to accommodate the variability in family forms, not all of which are predicated on genetic connections, and offer a more intuitively acceptable view of how and why familial relationships get set up: we desire the goods of intimacy and support they provide, and we choose to pursue them. The social artifact view's great weakness is that it seems to have no special place for genetic connections, and the data indicating that genetic ties are important to us cannot be simply dismissed.

I call the mediating conception I wish to offer the "genetic narrative" view of the family. This nomenclature suggests that the role of genetic connections in our lives can be seen, not as "gene calling to gene," but rather as a part of our interest in perceiving the connections between our lives and the lives of others—connections which add depth and richness to the continuing story in which we participate, and which can therefore be referred to as narrative connections.

Human beings seek to transcend their own immediate experience somehow—actually, in many ways. Family connections are a part of that desire—the desire to transcend finitude. Sometimes we focus on the drive to beat mortality by looking only at death. Indeed, one of the best-known arguments of the Stoic philosophers was designed to demonstrate that fear of or grief concerning death was irrational by pointing out that we do not lament the time before our birth, or before anyone else was born. But the drive for relationship with those to whom we are genetically connected, can, I think, be seen as an answer—in part—to this Stoic consolation. We are not personally indifferent to what happened before we were born. It represents a part of our story, the earlier chapters of which are a part of the ongoing narrative, and without which we cannot read well what is going on in the part occurring now. Families are often seen as ways of achieving a kind of immortality, and there's something to this, but we should bear in mind the possibility that they serve to help us achieve immortality in both directions, as it were.
GENETIC NARRATIVES: A REFLECTIVE CONCLUSION

The "natural kind" view of families suggested that untwisting the social, gestational and genetic strands of parenthood opens up children to a special kind of alienation and loss, and that the individual and social consequences of this loss are not fully known. This uncertainty ought to give us pause before going ahead with retailoring the substance of family relationships.

The "artifact" view suggested on the other hand that really none of this was so novel. All morally significant ties are really volitional ties, and any special distress occasioned by reproductive techniques that sunder genes and rearing would be a function of socialization not nature. As such, the distress would likely be less deep, more individualized, easier to handle.

The "genetic narrative" view points out that there really is an important kind of vulnerability to which children are exposed here, residing not in some brutally biological call of blood, but rather in the structures of meaning through which we try to make sense of our lives. What that may direct us to is an important element in meaning—moral and intimate relationships—which are part of what gives cohesiveness and quality to our lives, part of the way in which we feel both situated and recognized as individuals. The difficulty with either male or female surrogacy may not be in the experience of those who feel a great bond to the child they have helped create, but those who do not. For they are the ones who block an avenue of meaning to a child, and whose action may carry the implication that the child herself—her own story—is not significant to her biological father or mother, whose stories are bound up with the child's, its extensions into the past.

However, there is a possible fault lying near the heart of this attempt to marry the biological and the "meaning-seeking" aspects of human reality. Can the very phenomena that may be shown to lie at the heart of our abilities to seek for meaning themselves deprive us of any meaning our lives might have? Could deep knowledge of the structures that have allowed us to evolve into creatures who see their lives in terms of stories, with their open-ended character, actually transform those lives into things which can at base be understood fully through the non-narrative, more deterministic structure of scientific explanation? Our stories connect us to a fixed past, but they also open out into a future whose character is partly determined by what we do; they account for the character we have, but also provide the possibility of new challenges which give rise to
new decisions, which can transform our characters. To the extent that our genes provide the fundamental explanation for who we are and what we choose to do with our lives, to that extent the narrative character of life seems illusory.

This sort of worry is not only hard to allay, it is even hard to be sure one has stated it sensibly. But it seems real, for all that, and deserving of at least a partial answer. It may in fact turn out that the central task of bioethics is not to sketch out the appropriate character of informed consent, or even to pronounce on the morality of assisted reproduction, but rather to reflect on the implications of biomedicine's knowledge and power for what it is to lead a meaningful human life.

It may be worth bearing in mind in this connection that our seeking the truth of our genetic story is really a matter of the same drive for transcendence and completeness and connection that makes us look to our personal pasts and into our personal futures; from this perspective, science is important to us for reasons not unlike those which make families important to us. The end of our truth-seeking may reveal that we are not the coauthors of our own narratives, but rather highly determined by our genes and their interaction with our environment. If so, we may take some comfort from reflecting that we are an important part of a wider story than our own; we can still see ourselves as the part of the universe which has the ability to understand itself. Along with caring for those we love, and striving to make of the world a more peaceful and fairer place, the epistemic roles we play seem not without their own special dignity, even if the script turns out to be not our own.  

29. An earlier version of this essay was given as a lecture at Mount Union College in Alliance, Ohio. The lecture was given under the auspices of the GTE Foundation Lecture Services on Technology and Ethics. I am indebted to Mount Union College, and to the GTE Foundation for providing insight and reaction.