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Involuntary Childlessness, Reproductive Technology, and Social Justice: The Medical Mask on Social Illness

The past thirty years have witnessed a steady rise in the demand for treatment of infertility, including the use of in vitro fertilization (IVF) and third-party eggs and sperm. From 1995 to 2002, the number of assisted reproductive technology (ART) clinics in the United States grew from 300 to 428, the number of ART cycles performed rose from 59,142 to 115,392, and the resulting pregnancy rate increased from 24.4 percent to 34.3 percent (although the rate for live births was lower) (Jain 2006). The overwhelming majority of ART users are heterosexual married or cohabiting couples with some form of biological inability to reproduce without medical assistance or third-party collaboration, but gay and lesbian couples and single women and men also use technologies such as donor insemination, IVF, and surrogacy in hope of having a child. Such treatment is very expensive. Preliminary tests designed to locate the source of the difficulty in conceiving cost several hundred dollars. Drugs to stimulate ovulation (such as Pergonal, Follistim, and Gonal F) cost between $1,050 and $5,600 per cycle (Spar 2006, 24). In 2002, one authority estimated the cost of a single cycle of IVF at $9,547—an estimate that did not include medication costs (Jain 2006, 876; see also Spar 2006). The use of donor eggs or donor sperm pushes the cost higher still.

The high cost of infertility treatment has led many people concerned with the unfair effects of economic inequality on people's chances to have children to lobby state legislatures to require insurance coverage of (at least some) IVF treatments. These proposals would make reproductive technologies accessible to anyone with a health insurance plan in the United States, as they are through government-funded health plans in

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much of Western Europe. The push for mandatory insurance coverage seems quite attractive from a social justice perspective: recognizing the importance of having children to some people's identity and self-fulfillment, it attempts to distribute access to medical technology more equitably. Such distributive justice, achieved through mandatory insurance coverage of infertility treatment, seems to provide both the principle and the mechanism by which the United States could redress the advantages that accrue to the wealthy in their efforts to form families.

The campaigns for mandatory insurance coverage for infertility treatment are not, however, unequivocally a step toward greater justice. For one thing, they put a heavy emphasis on the genetic tie between at least one parent and the resulting offspring, which may suggest that adoption is a second-best way to bring a child into a family. For another, addressing infertility mainly by extending health insurance coverage suggests that infertility is an individual and private condition, a consequence of the luck of the draw in terms of physical capability and condition. This obscures the fact that a significant share of infertility stems from quite varied (and oppressive) social contexts that affect different populations: delayed childbearing, untreated pelvic inflammatory disease (PID), and workplace and environmental toxins. Infertility resulting from delayed childbearing disproportionately affects professional and white-collar workers caught in the double bind that presents them with the choice of conforming to the demands of the workplace and delaying having children or having a child in their twenties and being perceived as not sufficiently serious about their careers. Infertility resulting from PID, often the result of untreated sexually transmitted diseases (STDs) and HIV infection, affects mainly poor populations (disproportionately minorities). Infertility resulting from workplace toxins threatens mainly industrial and agricultural hourly wage-workers. Although often portrayed as solutions to the childbearing efforts of people in these different social contexts, reproductive technologies in fact mask the social and economic structures and inequities that give rise to the problem.[1]

In this article, we argue that considerations of distributive justice alone do not lead to appropriate policy regarding infertility and new reproductive technologies (NRTs). This issue illustrates the truth of Iris Marion Young's observation that "a focus on the distribution of material goods and resources inappropriately restricts the scope of justice" because it leaves untouched the social practices that underlie people's differing ability to act to affect their future and to develop and exercise their capacities (1990, 21–22). As Young points out, distributive justice is not identical to social justice: there is a difference between giving all persons equal rights and equal opportunity within the existing (and oppressive) system (i.e., distributive justice) and altering the conditions under which inequality or oppression arises (i.e., social justice). In the realm of infertility, advocates of social justice in family formation must attend to social factors that contribute to the incidence of infertility and to the construction of desires for particular kinds of children.

The way in which infertility treatment is described is not just a question of semantics: the focus on the individual and his or her "medical problem" is part and parcel of the tendency in the United States to ignore the ways in which social structures shape how people experience the possibilities of forming a family and to privatize responsibility for family well-being. As a consequence, measures that might prevent or decrease the incidence of infertility are ignored or slighted while attention is focused on "curing" individuals. Achieving social justice with respect to reproductive technologies requires changing our understanding of family formation from a matter of private choice and individual responsibility to a more comprehensive recognition that multiple factors, including public policy, influence the choices available to people seeking to form families. It also requires replacing the ideology of the self-reliant household with an acknowledgment of the collective—public and governmental—responsibility for the well-being of families and their members (Folbre 2001; Fineman 2004; McClain 2006).

In the first section of this article we discuss the incidence and causes of infertility in the United States and the inequity in access to infertility treatment, particularly IVF. In the next section we examine the argument that the importance many people place on having children justifies mandatory insurance coverage of infertility treatment in order to create greater equality of opportunity to obtain this important ethical good. The third section considers the dilemma that proposals requiring insurance coverage present for those of us who want to foster equal respect for all families. On the one hand, mandatory insurance suggests that everyone has an equal right to access the means of family formation; it undercuts the attitude that the reproductive desires of the affluent are worthy of respect while those of the poor are not. On the other hand, focusing on insurance coverage of infertility treatment diverts attention from potential policies centering on more aggressive treatment of STDs, tests for toxins that

[1] In an insightful analysis of popular pregnancy and infertility advice books, Helena Michie and Naomi Cahn (1997) point out that infertility books almost always assume middle-class subjects and audiences, promote medical solutions to infertility, and are devoid of social and political analysis.

negatively affect fertility, and measures to ameliorate the tension between remunerative work and family caregiving. Moreover, mandatory insurance does nothing to challenge the stereotype of feminine fulfillment through pregnancy or the correlation of masculinity and virility with remunerative labor and with producing offspring—particularly, male heirs—but not with caregiving. Advocates for social justice must weigh carefully the pros and cons of joining campaigns for insurance coverage of assisted procreation. The attainment of social justice requires work to keep the public eye squarely on not only the inequality of access to treatment of infertility but also on the underlying causes of much involuntary childlessness and the possibility of adoption as a way to bring a child into a family.

Infertility: Incidence, causes, and access to treatment

Infertility thwarts many people's desire to have a family. Medical authorities define infertility as the inability of a married couple to conceive after twelve months of unprotected sexual intercourse. "Impaired fecundity" refers to cohabiting as well as married couples; it encompasses the inability to have a baby for any reason other than a sterilizing operation and includes the inability to carry a baby to term or the lack of a pregnancy after three years or longer of trying to conceive (Chandra et al. 2005, 22). This difference in terminology complicates analyses and discussions of involuntary childlessness in the medical literature, but for our purposes we can reasonably follow the lay practice of referring to both conditions as infertility.

One of the most prevalent causes of infertility is the age of the woman attempting to have a child.[2] Female mammals are born with all the eggs they will ever produce, and as a woman ages, so do her eggs; with time they become less likely to be fertilized successfully. Women in their twenties possess the best possibility for fertility because their eggs are healthiest. Women in their early thirties have greater difficulty conceiving, and fertility plummets in women over age 35. Older women are not only less likely to conceive but are also more likely to conceive a child with genetic disabilities. The desire to avoid disability intensifies some people's desire for earlier childbearing or earlier access to infertility treatment. Despite the fact that women's fertility and physical energy decline after their early twenties, many women delay childbearing. A significant number of women

[2] On female age and infertility, see Evers (2002) and Tough et al. (2002). For a summary of research on male age and infertility (which is inconclusive about the existence of an effect of male age on conception), see Moskovtsev, Willis, and Mullen (2006).

are influenced by the difficulties they foresee in trying to combine remunerative work with child rearing.

A second cause of infertility is a blocked fallopian tube, which prevents the sperm from reaching the egg as it passes down the fallopian tube or which prevents the egg from reaching the uterus. Like advanced maternal age, tubal impairment affects women in all sectors of the population, but government sources indicate that delayed childbearing is more prevalent among white women than among Hispanic women and African American women, while tubal impairment occurs more frequently among Hispanic and African American than white women (Bitler and Schmidt 2006; Jain 2006). Tubal impairment is often the result of PID. Pelvic inflammatory disease occurs when sexually transmitted bacterial infections, most notably *Chlamydia trachomatis* (chlamydia) and *Neisseria gonorrhoeae* (gonorrhea), remain untreated or inadequately treated. According to the Sexually Transmitted Diseases Surveillance Data collected by the Centers for Disease Control and Prevention (CDC) for 2004, these infections disproportionately affect minority groups in the United States: chlamydia rates are seven times higher among African American females than they are among white females, while female gonorrhea rates among African Americans, American Indians and Alaskan Natives, and Hispanics are, respectively, approximately nineteen, four, and two times greater than for whites (CDC 2005). Since these groups disproportionately represent the most impoverished members of society—recent data reveal a 24.7 percent poverty rate for African Americans and a 21.9 percent poverty rate for Hispanics, compared to the 8.6 percent poverty rate for the non-Hispanic white majority (DeNavas-Walt, Proctor, and Lee 2005)—minority STD rates become visible as a product of overlapping and linked racial and economic factors.

Infertility also results from workplace and environmental toxins, although the effects are difficult to establish with precision (we confine our discussion here to workplace toxins). A dramatic example of the effects of workplace chemicals on fertility occurred in 1977, when a conversation among workers at an Occidental Chemical plant in Lathrop, California, about their difficulties in having children sparked an investigation by their union, which discovered that fourteen men were sterile (nine had sperm counts of zero), while another thirty-four had reduced fertility. The pesticide DBCP (dibromochloropropane) was identified as responsible, and the Occupational Safety and Health Administration (OSHA) issued strict standards thereafter (Daniels 2006, 118–20). This response was exceptional, however. By and large, there is little regulation of chemicals thought to adversely affect reproduction. In part this is due to the difficulty of

drawing a direct causal relationship between a chemical and impaired fertility. Effects on reproduction are the result of hormonal changes, and the mechanisms by which a substance affects these hormones are complex; moreover, such changes may occur either in the male or in the female partner and either before or after conception. Studies are further complicated because researchers often do not know the levels of exposure individuals receive at work. Compounding factors, such as cigarette smoking and drug and alcohol use, can also change the way a chemical affects a worker's reproductive capacity (Hatch 1984; Sharpe and Franks 2002).

Despite these difficulties, at least forty-eight chemicals are known or strongly suspected to have adverse effects on human reproduction. Studies have found "significantly higher rates of infertility . . . in women employed in several occupations, including dental assistants exposed to nitrous oxide, women exposed to glycol ethers in the production of silicon wafers in the semiconductor industry, and women exposed to organic solvents in a variety of occupations." Decreasing sperm counts "may occur through a variety of pathways, including exposure to pesticides [including DDT] or industrial emissions and/or ingestion of animal fat or contaminated drinking water" (Fidler and Bernstein 1999, 500; see also Sharpe and Franks 2002; Daniels 2006). In addition to these toxins, one thousand workplace chemicals have been shown to have adverse effects on reproduction in animals. Nonetheless, the "physical and biological agents in the workplace that may affect fertility and pregnancy outcomes are practically unstudied in humans" (Fidler and Bernstein 1999, 500), and OSHA has established few firm guidelines or rules governing reproductive hazards in the workplace (Daniels 2006, 127). When job options are few, some individuals may be left with no alternative but to accept a job that threatens both their health and their capacity to form a family.

Ironically, the frequency of infertility within a given population is in inverse relationship to that population's use of infertility treatment services. Poorer women and those who lack health insurance are less likely to go to a doctor for fertility assistance, and race, education level attained, marital or cohabitation status, and socioeconomic status all affect access to fertility services. The 2002 National Survey of Family Growth, published by the National Center for Health Statistics, revealed that only 8.2 percent of women of Hispanic or Latina origin and 8.4 percent of African American women surveyed had utilized infertility treatment services in the United States, compared with 13.8 percent of the non-Hispanic or non-Latina white women (Chandra et al. 2005). Those data also showed that 9.2 percent of the lowest poverty tier (defined as up to 149 percent of the poverty line) accessed any infertility treatment services, compared with 17.6 percent at the highest tier (300 percent of the poverty line or more) (Chandra et al. 2005). In other words, the very poor used fertility services only half as much as did wealthier members of society. Other studies have demonstrated that African American women and Latina women underutilize infertility treatment services and that the majority of patients are white, highly educated, and well-to-do (Jain and Hornstein 2005; Bitler and Schmidt 2006; Jain 2006). This is not surprising, because "disparities related to race, ethnicity, and socioeconomic status pervade the American healthcare system" (Agency for Healthcare Research and Quality 2004; quoted in Jain 2006, 880) and also, perhaps, because some studies of African American family life have argued that there may be less emphasis on the genetic tie among African American families than among white families (Stack 1974; Roberts 1995; hooks 2002).

The correlation of socioeconomic status and educational level with the use of infertility treatment reflects the extraordinary expense of high-tech infertility treatments like IVF (Stephen and Chandra 2000; Bitler and Schmidt 2006). Treatments for infertility range from the moderately costly to the very expensive. In 2002, the mean cost of an IVF cycle in the United States, including preliminary testing and medications, was between $10,000 and $15,000. The median household income in the United States that year was $42,409, so a single cycle of IVF exceeded 30 percent of an average family's income, placing it virtually out of reach (Jain 2006). Use of donor eggs entailed additional expense; the lowest cost for donor eggs in 2003 was between $3,000 and $4,000, but prices could stretch up to $25,000 in some areas for eggs from particular kinds of donors (Spar 2006).

There are striking differences in the socioeconomic characteristics of those who turn to reproductive technologies and advanced drug treatments for infertility and those who do not. Differences in the distribution of household income among racial groups mean that economic disparity is certain to contribute toward "African American and Hispanic households being more likely to be shut out from access to IVF treatment" than are white or Asian households (Jain 2006, 877). In addition to their low earnings, low-income workers often have no insurance coverage. Even those with insurance are rarely covered for infertility treatment. Poor women have greater rates of infertility than do middle-class women, but they receive less infertility treatment and are exposed to more childbearing-related risks than more privileged women. Infertility, then, is not only a medical problem requiring individual treatment but also a reflection of group inequalities that calls for rectification through public policy.

The case for mandatory insurance coverage for IVF: Equal access and respect for families

The unequal access to ARTs created by their staggering cost has led some people to argue that access to infertility treatment, including both drug treatment and access to NRTs, must be equalized by mandating that at least some procedures be covered by health insurance. The debate on this issue is extraordinarily complex because it involves questions of whether the right to health care (if such a right exists) includes a right to a biologically related family and whether and in what ways infertility is comparable to medical conditions covered by insurance. We cannot examine these topics comprehensively, but we believe that the right to a chance to have and raise children entails (where it is economically feasible, as it is in the United States) a right to health care and to infertility treatment (including some IVF). There is significant disagreement on the question of whether those who are not economically self-supporting should receive assistance in their attempts to have children and, by extension, to receive support for caregiving or sustaining family life.[3] We claim that, at a minimum, some treatment for infertility should be covered by health insurance.

Many advocates of public provision of health care (some form of universal health insurance, whether fully public or a mixture of public and private) focus on the fact that health is a basic need or primary good. Drawing on John Rawls's work, Norman Daniels, Bruce Kennedy, and Ichiro Kawachi argue that health care must be part of a just society because health care protects individuals' access to the normal range of opportunities in their society (Rawls 1971; Daniels, Kennedy, and Kawachi 1999). Dan Brock joins Daniels, Kennedy, and Kawachi in claiming that health and health care are essential to distributive justice because those suffering ill health are most likely to be deprived of other basic goods such as wealth, position, opportunity, and security—and those deprived of these other basic goods are most likely to suffer ill health (Brock 2000).[4] Amartya Sen, for his part, takes a somewhat different approach, defining justice not as the proper distribution

[3] At one time Massachusetts covered infertility treatment for women receiving public assistance. When the law came up for renewal in 1994, many people expressed outrage that women who could not support the children they already had should receive public assistance to conceive another child (King and Meyer 1997). Charles A. Murray (1984) and Lawrence M. Mead (1986) argue against reproductive rights for those who are not self-supporting. Others argue that depriving the poor of the right to have children (Nsiah-Jefferson and Hall 1989; Ikemoto 1996)—or removing children from parental custody because of poverty (Mink 1999; Roberts 2002)—is unjust.

[4] Patricia Smith observes that the linkage between poor health and other deprivations "is not just a vicious circle[;] it is a vicious downward spiral" (2002, 302).

of basic goods but, rather, as the fulfillment of society's obligation to provide people with those resources needed to develop essential human capabilities. His reorientation of the discussion from an income-centered to a capabilities approach is particularly relevant to the ability to establish a family, because the capabilities approach understands the problem of poverty not primarily as one of inequality but, rather, as the lack of freedom that inequality brings in its wake (Sen 1992).

Several theorists argue that procreation and parenting are of such central importance to many individuals' identity and life goals that raising one's own offspring warrants respect and protection (Schoeman 1980; Brighouse and Swift 2006). Others extend that position and assert that giving everyone equal opportunity to choose whether or not to parent a child means that medical insurance should pay for infertility treatment. Brock, for example, asserts that when persons cannot, through no fault of their own, reproduce without high-tech assistance, then "those means should be secured . . . as part of the basic welfare rights of all citizens and as necessary for equality of opportunity to construct and pursue one's own plan of life" (Brock 1995, 193; see also Brock 1996). Also claiming that having and raising genetically related offspring is "a constitutive element of leading a good life" for many, Justine Burley argues that "justice demands that individuals be compensated for all or part of the costs of the assisted conception techniques that they undergo" (1998, 142, 129). Mary Anne Warren agrees with those who claim that "distributive justice requires universal access to these medical services for infertility, within the limits of the available medical resources and other social needs" (2002, 426). Covering the cost of NRTs is a mechanism by which equal opportunity with regard to a fundamental good (Rawls 1971) or the capacity to exercise a fundamental human capability (Sen 1992) can be achieved.

Whether to characterize infertility as a medical condition requiring medical treatment and warranting coverage by health insurance is a thorny question. Infertility is not life threatening, and it does not make people incapable of performing normal daily tasks, but its psychological effect can be profound. Although the purpose of infertility treatment is to form a family, not to cure a disease, the facts that diagnosing infertility often requires medical testing and that treatment, whether by drugs or reproductive technologies, requires a doctor emphasize the medical rather than the social dimension of infertility. And given the extraordinary costs of infertility treatment to individuals, including treatment for infertility in medical insurance seems to be a practical way to help the infertile across some economic classes.

Requiring that health insurance policies include infertility treatment as

a benefit, however, has so far not altered patterns of access significantly. An April 2006 study that examined the fifteen states that provide insurance mandates for infertility found "no evidence that these mandates have mitigated the disparities in treatment by race, ethnicity, or SES [socioeconomic status]" (Bitler and Schmidt 2006, 864). One group did benefit from the mandates: highly educated women over thirty years of age. The investigators concluded that "despite the rhetoric of expanded access accompanying passage of the mandates, these laws may not be reducing existing disparities in treatment" (864). The explanation may lie in the fact that many of the near poor, including those who work full-time, and even many of the middle class do not have health insurance and, thus, mandatory coverage of infertility treatment will not affect them, but "highly educated women 30 and older are . . . the group most likely to have private insurance" (864). The indigent receive medical benefits under Medicaid, but no state offers infertility treatment as part of its Medicaid benefits (King and Meyer 1997). Treating infertility by mandating that insurers cover IVF and other NRTs can create greater equality of opportunity to form a family only under a system of universal health insurance.

Universal coverage of (at least some) infertility treatment would in all likelihood not be prohibitively costly, despite the fact that IVF is expensive and other medical treatments compete for funding (Van Voorhis et al. 1998). Maura Ryan asserts that "one of the most persistent and pervasive myths concerning the costs of treating infertility is that IVF is a uniquely expensive response to infertility, therefore that the costs of treating infertility can be controlled simply by excluding IVF" (2001, 19). But, in fact, NRTs may be cost-effective compared with other techniques. For instance, there is general agreement that IVF is as cost-effective as surgery in treating infertility due to blocked fallopian tubes, but IVF is less often covered by insurance plans. Furthermore, in some cases other NRTs are the only option acceptable to the client. For example, in treating male-factor infertility, intracytoplasmic sperm injection (ICSI) achieved a pregnancy rate of 24 percent per cycle, while donor insemination resulted in a pregnancy rate of 9 percent; however, the cost per delivery of using ICSI-IVF was $89,009, significantly greater than that of using donor insemination (Van Voorhis et al. 1998, 999–1002). But for men whose religion prohibits using donor sperm (Islam is one such religion), ICSI may be the only way to have a genetically related child (Inhorn and Fakih 2006).

A number of recent studies suggest that even though the cost of treating any individual runs in the tens of thousands of dollars, when that expense is spread out over the population of the insured, coverage for infertility results in only a small increase in premiums. In 1995, an analysis of IVF

services in the United States "estimated that the cost of adding IVF services to a health plan in 1995 would be $2.79 per person per year. This represents less than one tenth of one percent of the total health benefit cost of a typical policy" (Van Voorhis et al. 1998). Reviewing the data in 2002, researchers commented that it seemed as if "the additional cost of covering in vitro fertilization is still likely to be a small fraction of the total cost of a family plan" (Jain, Harlow, and Hornstein 2002, 666). The University of Iowa offers a fee-for-service health care plan that includes coverage for infertility treatment. An analysis showed that "infertility diagnoses and treatments accounted for 0.85% of the total health care costs. . . . Infertility costs in 1995 were $0.70 per member per month ($8.40 per member per year)" (Van Voorhis et al. 1998, 1003). These costs were similar to those in the United Kingdom and New Zealand, where the costs for infertility treatment under national health insurance were estimated to be $4.62 and $2.35 per person per year, respectively (1003).

Some people worry that if IVF were covered by insurance, more people would seek treatment and thus increase the cost to insurers (Neumann 1997). But even with large utilization increases, premiums would not be likely to rise greatly, in part because many people would choose IVF rather than the less cost-effective tubal surgery. In addition, policies could limit the number of cycles the insurance would cover (many people mention three cycles as a reasonable number), or cap lifetime benefits at some amount (say, $30,000), or permit the implantation of only three embryos per cycle in order to avoid the enormous expenses and health risks associated with multiple births (Van Voorhis et al. 1998). Indeed, such regulations make sense not only in terms of cost-effectiveness but also in terms of social justice. In providing some access to all members of the population, society sends the message that it recognizes the value of procreation to all its members; in capping benefits, society signals that reproductive technologies are not a panacea and carry with them their own problems.

Considered from the perspective of those who try to make up for the effects of economic inequality on people's opportunity to have and raise biologically related children, requiring insurance coverage for infertility treatment appears desirable. But such coverage, as we have noted, achieves this goal only if it is universally available.[5] And other considerations suggest that focus on insurance coverage deflects attention from how to diminish the incidence of infertility; making conception possible is desirable, but

[5] Equalizing people's chances to have a viable family life also requires a social safety net and support for caregivers, an argument developed in Shanley (2009), but these arguments are beyond the scope of this essay.

preventing infertility is more desirable. Moreover, some of the causes of infertility are not only preventable but themselves reflect conditions of social injustice. Among professional women and their male or female partners, employment structures that offer strong incentives for delayed childbearing and penalize staff members with child-rearing responsibilities not only increase infertility but also reinforce gender-based inequality in home and public life. Agricultural workers exposed to pesticides and industrial workers exposed to various toxins often face the Hobson's choice of working under hazardous conditions or not working at all. In the face of the unequal resources of capital and labor, unions must make reproductive health—traditionally considered a "woman's issue," not a labor issue—a priority. In poor and minority communities, both the lack of sex education about the threat that STDs and HIV pose to fertility and the lack of medical treatment for STDs, HIV, and PID reflect the relative unimportance attached to the reproductive aspirations of marginalized communities.[6]

Also complicating the question of whether proponents of social justice should support mandatory insurance coverage for infertility treatment is the fact that the intimacy, mutuality, and intense connectedness that characterize parenthood are not limited to those who raise children to whom they have biological or genetic ties. In contrast to the arguments that many supporters of insurance-funded ART put forward, the experiences of deeply involved and fulfilled adoptive parents call into question the necessity of a biological connection to establish a meaningful parent-child bond. Adoption is also a way of bringing a child into a family, and policies related to infertility treatment and adoption alike should always take into account the effect of one on the other. In an essay on the ethical demands of collaborative reproduction, Adrienne Asch reflects, "If founding families and raising children is thought crucial for many people's fulfillment, perhaps society should support collaborative reproduction and adoption through private insurance and thus aid people who would be parents" (Asch 1995, 234). In addition to insisting that any mandatory insurance for infertility treatment be universal, those concerned with helping adults become parents should insist that it not make infertility treatment a less expensive choice than adoption.

Public policy would be foolish and wrongheaded, with regard not only to adults but also to children, to privilege biological procreation and create

[6] *The American Journal of Bioethics* published an informative and provocative symposium discussing whether IVF treatment should be available to people with HIV. Ten authors responded to the lead article by Mark V. Sauer, "Providing Fertility Care to Those with HIV: Time to Re-examine Healthcare Policy" (2003).

incentives for couples to embrace reproductive technologies rather than adoption. We should "ensure that couples seeking treatment for fertility problems are cognizant of opportunities to adopt, and do not face disincentives to do so" (Neumann 1997, 1232). At the same time, it is vitally important to recognize the injustice of "freeing children for adoption" when the provision of social services and supports would enable an economically struggling family to stay intact instead. The desire of infertile persons to raise children is not a reason sufficient to justify the removal of children from otherwise adequate homes that lack certain resources that society could supply. It is crucial that discussions of infertility always keep front and center the facts that the goal of achieving a family can be met in a variety of ways, and that a social justice approach is required to evaluate the relationship of these ways to one another as well as the ethical issues each raises individually.

Why mandatory insurance is not enough to achieve social justice in reproductive life

The argument that the right to have and raise children means that we should use mandatory health insurance coverage to get rid of (or at least reduce) the class-based inequality of access to reproductive technologies can only partially redress a problem that is itself in part created by established social structures. There is no evidence that such mandates have in fact mitigated disparities in race, ethnicity, or socioeconomic status (Bitler and Schmidt 2006). And, statistically, those who turn to IVF take health risks during treatment, run the risk of multiple births, and have a small chance of success (Green 2004). A far better approach would be to address those causes of infertility that are within human capacity to control or ameliorate.

The trend toward delayed childbearing

Beginning professionals and white-collar women workers experience a double bind that presents them with the choice of conforming to the demands of the workplace and delaying having children, or having a child in their twenties and being perceived as not serious about their careers. Michele Goodwin has argued that "for those who commit to an early career, which can be perceived as a 'selfish' life plan, the process to promotion and job security can take an initial eight to ten years, leaving such women either at the cusp of fertility decline or over the edge. . . . Thus, both options, early career and delayed child bearing or early maternity and postponed career, are burdened choices" (Goodwin 2005, 47–48). Given gender role expectations and the assumption that women will provide the majority of child

care, this double bind is experienced almost exclusively by women. Indeed, once a man has a family to support, he may create the impression that he has settled down and will be a more dedicated worker.

Assisted reproductive technology may appear to provide a solution to the double bind, enabling women to cancel out the effect of age on fertility, but it is far from a comprehensive solution. The hope that ART will overcome the infertility attributable to advancing age is usually not realized: only 20.5 percent of ART cycles for women between the ages of thirty-eight and forty result in a live birth, and for women older than forty-three the rate of success is about 2 percent (Goodwin 2005, 35). Moreover, focusing on ART diverts attention from the workplace structures and practices that both create the double bind and contribute to women's subordination in the family and in civil society.

There are workplace reforms that would alter the context in which people make decisions about paid labor and caregiving.[7] Workplace practices could facilitate shared parental responsibility both for the effort that goes into caring for children and for those children's economic support (Gornick and Meyers 2003). Child care centers, which would need to be subsidized so that they would be equally available to all children, would be available to supplement parental care. Workplace policies that assume that all workers have caregiving responsibilities would be a radical change from the present assumption, but such policies are both possible and desirable.

The charge that mandating paid maternity leave or child care facilities would constitute undue state intervention in the private life of the family misunderstands the ways in which state action (or inaction) already implicates the state in family life. Any organization of work affects the options people have as they arrange their personal and family lives, and the idea that the state has the option to intervene or not to intervene in the family is an illusion. Years ago, Frances Olsen discussed the myriad ways in which the state sets background rules that influence people's interactions within families. The question is not whether state action affects the family but how it affects the family (Olsen 1985; see also Olsen 1983 and Okin

[7] As remunerative work moved out of the home following the Industrial Revolution, the workplace was structured on the assumption that full-time workers (assumed to be male) had a full-time wife at home. Despite the fact that in the twenty-first century only a minority of families conform to this division of labor, wages and workplace practices still reflect this assumption. In 2004, women who worked full-time year-round earned a median wage of $31,223, while men earned $40,798, a ratio of 76.5 percent. This was up from 65.2 percent in 1987 but is still a significant gap (Institute for Women's Policy Research 2005). In addition, most workplaces continue to have inflexible hours and allow little time off to attend to pressing family matters.

1989). Critics may term proposals to facilitate participation in the labor force by people responsible for rearing children "interventionist," but in doing so those critics ignore the ways in which present practices already profoundly influence family life.

Current workplace arrangements are anything but neutral with regard to the gender caste system: they affect people's decisions about who should sacrifice remunerative labor in order to provide adequate care to infants and young children (and single parents lack even this choice). The ways in which work is organized (full-time, continuous, physically distant from the place where children are being cared for, etc.) are human constructions and are essential parts of what makes gender a caste system. The way to begin dismantling the gender caste system is to assume that all human beings have a right to enter into sustained caregiving relationships and a right to social conditions, including work structures, that make the maintenance of those relationships possible.[8]

Although proponents of ART often present it as a way to extend women's childbearing years, permit greater choice in career patterns, and equalize women's and men's work experiences, this focus on ART diverts attention from the workplace practices that lead women (and their partners) to postpone childbearing and child rearing in the first place. If the new technique of freezing eggs comes to be seen as a promising means of delaying family building and avoiding the potential need to obtain eggs from others, even more women may postpone childbearing. We think it crucial to urge workplace reform rather than engage in ever more enthusiastic adoption of yet another expensive and medicalized means of achieving parenthood. Goodwin notes that "ART accommodates the very social inequities which limit women's opportunities to simultaneously pursue careers and families equal to their male counterparts. Thus it indirectly reifies problematic norms by providing a secondary 'out' for the private sector by appearing to provide an unburdened utopian dream for women" (Goodwin 2005, 52).

The inadequate treatment of PID

In the absence of more aggressive policy initiatives, the unequal rates of STDs, PID, and infertility across racial and socioeconomic groups are likely to continue. Considering that 40 percent of chlamydia cases result in PID and that of those resultant PID cases, one in five of the women becomes infertile, no discussions of infertility prevention in the United

[8] Depending on how much child care they hire others to do, the rich deprive themselves of some of the learning and growth that adults derive from taking care of children and may, in turn, deprive those they hire of the ability to take care of their own children.

States can ignore the devastating role of STDs and HIV and their links to minority groups.

Because of this network of STDs, PID, HIV, and infertility, preventing infertility is best addressed by implementing an array of public health measures, including prevention and screening of STDs and HIV and education about the short-term and long-term risks of unprotected sexual activity. As both chlamydia and gonorrhea disproportionately affect women under the age of twenty-five, screening is very important for sexually active adolescents. Despite a CDC recommendation that both men and women receive annual screening for chlamydia, researchers found that in the mid-1990s only one in five sexually active U.S. female adolescents was "receiving recommended [STD] screening, even if they were receiving routine health care" (Fiscus, Ford, and Miller 2004, 235). Meanwhile, another study found that "receipt of sexual health services was particularly rare for all boys and for girls whose primary language was not English" (Lafferty et al. 2002, 1781). These studies suggest large unmet needs in sexual health care for adolescents and young adults. Even when health care is available, then, it often is inadequate for the population served.

More aggressive spending and programming in terms of chlamydia screening and treatment have succeeded in curbing PID rates in the past. A 1996 study of a health maintenance organization in the northwestern United States found that selective testing for cervical chlamydia and subsequent treatment could result in a decreased rate of PID; in this case, the decline was 56 percent one year after screening and treatment (Scholes et al. 1996; see also DeLisle 1997). Integrating screening into standard health care (physicals, annual checkups, etc.) can serve as a method by which to further combat STD-caused PID and to reduce chances of subsequent infertility. Such a program avoids the damage done to those affected and is more cost-effective than current programs that emphasize the treatment, not prevention, of STDs and STD-caused PID (Hillis and Wasserheit 1996; see also Pourat et al. 2002).

This restructuring of health care services must be accompanied by concerted efforts to educate about STDs, their prevention, their treatment, and their effects. While most secondary schools across the United States have some sort of sex education classes, programs that receive federal funds "are prohibited from using their grants to advocate contraceptive use," despite research showing that "public support for instruction on condoms and other contraceptives is almost as high as that for abstinence instruction" (Landry et al. 2003, 267). The emphasis on abstinence education leaves adolescents with little knowledge about how to prevent STDs or where to receive treatment and screenings for STDs. This lack of information, coupled with an existing system of medical treatment that does not give priority to STD screening, contributes to the incidence of infertility.

The failure to regulate toxins in the workplace

A comprehensive approach to preventing infertility must also take into account that public health measures concerning the workplace and the environment can affect infertility in both men and women. Responses to the reproductive threats posed by workplace toxins have so far been inadequate, not only because of the challenges to establishing the biological mechanisms at work but also because of the tendency to treat infertility as an individual and idiosyncratic medical problem rather than as a matter of public health. The perception of infertility as primarily a woman's issue has meant that people have not associated infertility with the workplace, traditionally a male space. An indication of the cultural separation between the family world and the work world is the fact that workers' compensation provides financial compensation "only for harm that prevents a worker from performing his or her job," not for job-related damage to a worker's body that precludes childbearing (Daniels 2006, 127).[9] An adequate response to workplace toxins requires far more serious thinking about the environmental—and, hence, public—dimensions of infertility and about the interconnectedness of gender, reproduction, and remunerative labor than has yet taken place.

Doctors and workers alike lack awareness of the reproductive problems that can stem from occupational exposure to certain chemicals. An observation by Tony Mazzocchi, a longtime labor advocate, captures this dimension of the problem: "If someone's got a reproductive problem, the first thing they're going to do is think that there's something wrong with them. If you have a problem reproducing today and you go to your clinician, that doc probably wouldn't know from bones about an environmentally caused problem. We try to say, what's the first thing you should ask a person? 'Where do they work, what do they work with and under what conditions do they work with it?' We don't currently train people to do that" (Anthony Mazzocchi, interview by Cynthia Daniels, quoted in Daniels [2006, 128]). Until both medical personnel and the general public receive such education

[9] American law is not monolithic on the question of whether deprivation of a parent-child relationship deserves governmental recognition. Although workers' compensation laws require no compensation for workers whose reproductive systems are damaged by workplace toxins, the Supreme Court held in *Bragdon v. Abbot* (524 U.S. 624 [1998]) that a biological dysfunction that hinders reproduction is a disability under the Americans with Disabilities Act of 1990 (U.S. Public Law 101-336, 104 Stat. 327 [1990], 42 U.S.C. 12101 et seq.).

and training, the workplace conditions that contribute to infertility rates will remain unstudied and unchanged.

The assumption that it is acceptable for a company to exclude women (but not men) from a workplace because of potential fetal damage from lead exposure was challenged before the U.S. Supreme Court in *UAW v. Johnson Controls, Inc.* (499 U.S. 187 [1991]). In *Johnson Controls*, the Supreme Court held that women could not be categorically excluded from a workplace in which batteries were assembled when men were not excluded. The plaintiffs argued that the company's policy rested on three impermissible assumptions: first, that all women could be treated as potentially pregnant persons unless they had been sterilized; second, that someone other than the woman herself should make the decision about whether or not she should work; and, third, that women are not an intrinsic part of the workforce and so do not warrant the same protections against loss of wages or seniority as men do. As Justice Harry Blackmun wrote, "Concern for a woman's existing or potential offspring historically has been the excuse for denying women equal employment opportunity. . . . It is no more appropriate for the courts than it is for individual employers to decide whether a woman's reproductive role is more important to herself and her family than her economic role" (*Johnson Controls*, 211). The Court found Johnson Controls's rationale—that fetal protection necessitates women's exclusion from battery assemblage—to entail unacceptable trade-offs between a woman's responsibilities to her family and to her employer. Requiring women to be sterilized in order to keep a job requires them to give up their ability to have and raise children in order to conform to the demands of a workplace designed around men's reproductive and social needs.

But although it rejected the gender stereotyping and inequality in Johnson Controls's employment policy, the Court could address only the questions put before it.[10] The justices' decision did not address what levels of hazards are acceptable for any worker or whether other aspects of the workplace need to change in order not simply to avoid infertility or harm to a fetus but also to enable women and men to take on the responsibilities of both family and work. With respect to our contention that there is a public responsibility to remove humanly created and rectifiable impediments to childbearing, the defeat of the employment policy at Johnson Controls leaves two vast policy terrains to be addressed: the reduction of toxins in the workplace and the dismantling of workplace practices that

[10] A summary of legal developments since *UAW v. Johnson Controls, Inc.* can be found in Hoeksma (2005).

pit workers' responsibilities to family and to a job against each other. Social justice requires that it be possible for men and women who wish to engage both in remunerative labor and in family caregiving work to do so.

Conclusion

Providing health insurance coverage for infertility treatment, while attractive as a measure of distributive justice, will not spur the changes in the public's understanding of infertility that are crucial to achieving social justice. Focus on insurance to treat infertility masks the fact that delayed childbearing due to workplace pressures, untreated STDs, and the existence of toxins in the workplace are responsible for a significant amount of infertility. To promote mandatory insurance coverage for infertility treatment before putting considerable effort into changing social structures that now increase the incidence of infertility is to reinforce the mistaken idea that the inability to form a family is a private trouble rather than a public issue.[11]

Forming a parent-child bond is an important component of many adults' conception of a good life, and for many, a biologically related child is so integrally a part of this aspiration that it justifies measures to reduce inequalities in people's chances of having children. Many people argue that the way to provide this remedy is through mandatory health insurance coverage of infertility treatment, with some measures to cap the expenses involved. There is a dilemma in this position, however. On the one hand, mandatory insurance coverage places the power of the state (and, therefore, of society as a whole) behind the proposition that money alone should not determine people's ability to access reproductive technologies. On the other hand, such coverage reinforces the perception of infertility as an individual medical problem to be overcome by medical means rather than as a problem stemming in part from social structures and public policies.

In privatizing and medicalizing the approach to infertility treatment, proposals for mandatory insurance coverage divert attention not only from public health and preventive measures but also from adoption and from ways in which people who do not have parental responsibility for a child can nonetheless be involved in significant ways in the child's upbringing. If it takes a village to raise a child, broader social reform would encourage adults—the involuntarily childless and the voluntarily childless, as well as parents—to have greater involvement with the children around them.

[11] On the public dimension of private troubles, see Mills (1959).

Giving social recognition to adults who take on substantial, albeit non-parenting, roles in the lives of children (e.g., aunts and uncles, godparents, parents' friends, caregivers, mentors, teachers, coaches, and others) would make the lives of many childless people more satisfying and might help those exhausted parents who say that they and their children could use more than one or two caring adults in their family circle. Our society would do well to look beyond traditional, biological notions of the nuclear family in order to enlarge the place of caring adults in the lives of parents and their children and expand networks of social support.

Although we have focused here on access to reproductive technologies, the claim to public support for the parent-child relationship is even stronger for existing relationships than for potential relationships. Here, again, the campaign for mandatory coverage of infertility treatment cuts both ways. It suggests that all people have a right to form a family, but it offers help in the form of assistance to conceive a child whose well-being then becomes the private responsibility of those who will raise it. There is no suggestion that the maintenance of the parent-child bond necessitates supports that will make successful parenting possible, such as jobs that pay a living wage, family leave time, and affordable child care.

The question of what people are owed with respect to the ability to access infertility treatment must be part of a larger inquiry into what people are owed as social beings who need certain kinds of intimate relationships in order to flourish. Peggy Cooper Davis argues persuasively that the forming and maintaining of family ties is a right of U.S. citizenship (Davis 1997). The capacity to form a family elicits civic regard as well as personal happiness, and it should ground the claim for assistance in both forming and maintaining parent-child relationships. People who desire children but are incapable of childbearing suffer emotionally, as do people who are incapable of raising their children, who are also stigmatized for their inability to sustain a family. It is of the utmost importance to consider the proper role of the state not only in helping people to form parent-child relationships but also in maintaining those relationships once they have come into being (Shanley 2009).

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Kristin Bumiller

The Geneticization of Autism: From New Reproductive Technologies to the Conception of Genetic Normalcy

Over the past fifty years, there has been a dramatic change in the social construction of autism from a psychiatric disorder to a genetic disease (Melendro-Oliver 2004; Nadesan 2005). Both professionals and laypersons saw this new theory of the cause of autism as instrumental in discrediting the insidious mother-blaming in both popular and medical accounts of autistic disorders. By most accounts, this new scientific evidence provided a factual basis to dismiss mythologies about pathological mothers and wild children and to begin a new era in which autism would be treated as a biological disorder. The biological understanding of autism was constituted as a medical truth that could be the basis of remediation therapies and possibly a cure.

This change does not simply concern the discovery of a new truth but rather is reflective of a complex social and political transformation within the medical profession and its growing control over bodies and identities (Clarke et al. 2003; Lock and Farquhar 2007). This shift has been termed "biomedicalization," the turn toward utilizing science for enhanced control over the body and its internal nature and expanding the reach of medical technologies in everyday life (Clarke et al. 2003). Biomedicalization has led to the production of new knowledge about health, disability, and illness that both affirms the role of scientific and technological innovation and opens up the possibility for patient-based social movements (Clarke et al. 2003) This transformation is clearly evident in the autism field. Once the purview of a few psychiatric specialists, it has now become a research domain for a wide range of behavioral specialists and biomedical scientists, and this domain is now backed by the activism of parents of autistic children.

Feminist scholars have investigated the consequences of biomedicalization and its relation to other illnesses and disabilities. This research has demonstrated the complex negotiations between citizens and the forces of technological power. These relations were first explored in studies that examined how women struggle to maintain their own interests and rec-

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