Comments on Rebecca Kukla's "Infertility, Epistemic Risk, and Disease Definitions"

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This is a thought-provoking paper, from which I learned a lot. My response will consist, first, of a few broad observations; then I will quibble about one point; finally, pose more targeted questions, about the practical implications of Professor Kukla's analysis.

What interests me most are issues somewhat tangential to the paper, but surely suggested by it: questions about alternative forms of family, about healthy structures for the rearing of children. As Professor Kukla urges, we are breaking through heteronormativity and the narrow ideal of the nuclear family – but what follows? Too many children are ill-served in the society that is emerging. We have ideas – politically impossible ideals – about what public services should be available. But do we have any ideas about what social structures to endorse and encourage? For many decades what we call "political and social philosophy" has been largely political; when it addresses private life, it does so to attack oppressive norms. But an absence of norms is neither possible nor desirable. Perhaps it's time to start considering what structures would better serve children – and, for that matter, adults—and encourage them.

My next comments are more directly relevant to the paper. I am interested in the variety of ways in which adults can "have" children; i.e., have strong and intimate relationships with the next generations. Adoption is one alternative, but there are others, much less recognized. The

urge to have a child biologically one's own provides the context for the paper; that urge might be less urgent if our cultural archetypes included more of "the village": besides parents (biological or adoptive) and grandparents, let's include aunts and uncles – not only the Auntie Mame types, but any adults closely involved in a child's life. One casualty of contemporary assumptions about the nuclear family is that our literature offers few archetypes of non-parental adults who shape the lives of children. (Teachers are perhaps the one exception.) Those other adults need not be officially related; most cultures use some form of "auntie" (and "uncle") broadly, to refer respectfully. African Americans refer to "other mothers." I've held such a role, and had such an aunt. The rewards on both sides of those relationships have been deep -- different from parenting, but deep.

My next point is a detail. Professor Kukla writes that "Medical treatment is not the standard response to social risk." In fact, however, medical interventions for social problems are common. Examples include psychoactive drugs, like Ritalin for children with ADHD, and Prozac for adults. Cosmetic surgery, from the "nip and tuck" of face lifts through correction of facial deformities, is done to address social problems. In years long past, girls who were considered too tall and boys who were very short received surgeries and hormone treatments.

Now I will turn more directly to the paper's specific concerns. First, it argues convincingly that infertility should not be classified as a disease. It is the result of diverse factors; treatments for those factors vary and sometimes conflict. This point made me wonder whether and how often infertility is actually classified as a disease, as opposed, for instance, to a condition around

which a variety of investigations and interventions cluster. I'm not sure what terms, for instance, insurance companies use to determine coverage. "Diagnosis" does not always refer to disease, even in the dictionary. I recall a hospital official saying that the most common diagnosis for admission was labor – childbirth. He did not consider childbirth a disease.

This, however, does not weaken the paper's overall argument. My most important set of questions has to do with the cash value of its analysis; can we get the rubber a little closer to the road?

The paper is completely successful in showing how sloppy are the various definitions of infertility. (I am tempted, though, to offer a more satisfying definition: Non-achievement of a viable pregnancy after x years of regular heterosexual intercourse with a fertile partner. Both "x" and "regular" would have to specified, somewhat arbitrarily, but boundaries are a bit fuzzy for many conditions.)

A deeper issue, though, arises from Prof. Kukla's question "Why is this [the set of definitions] such a mess?" One possible answer is that though it's a philosophical mess, but in the practical sphere the messiness just doesn't matter. Along the same lines, surely we want the embedded social norms to be omitted. That would be a step in the right direction, toward liberation. But are those embedded norms otherwise harmful? In particular, given the focus of this paper, do they affect who gets treated, or whose treatment is reimbursed by insurance? One possible answer is yes; i.e., women (straight or lesbian) who want to achieve pregnancy through a sperm

donor. “Rate of exposure” would be minuscule, compared with a couple having heterosexual intercourse. Research here is scant.

I would call this an epistemic loss, rather than risk. I suggest that “risk” applies only when probability does: tight and loose standards for diagnosis affect the likelihood of including those without the condition, or excluding those with it. The term makes the most sense when we have a straightforward understanding of what the condition is, e.g, being infected with HIV. With no such standard against which to measure definitions of infertility, epistemic loss -- missed truths – is the preferable term. The loss here is that evidence is not being generated, because the questions being asked are too narrow. That seems clear in the case of women wanting to become pregnant through donated sperm. I do not know if there’s a parallel issue for men.

So, in summary: The paper suggests broad issues about the place of children in our lives and in society; is mistaken, I think, about medicine and social (as opposed to physiological) problems; shows the rather wild inconsistencies among various definitions of infertility; and argues successfully for its categorization as a condition rather than a disease. Thank you, Rebecca.