

The Impact of the Family Unit on Reprogenetics

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The family unit, in our modern and contemporary settings, has seen a momentous paradigm shift. The traditional notions of family, for instance, have become much more open to fluid interpretation and definitions. With the enlargement of the scope of equality and non-discrimination rights, parents of the same-sex in some jurisdictions, are no longer prohibited from having their own children. In the United Kingdom, the once-controversial Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 allows mitochondrial donation in in-vitro fertilization, to birth a future child free of mitochondrial disorders. This has more commonly been referred to in the mainstream media as „three-parent-DNA“ situations. And although some jurisdictions impose stringent and very strict criteria on the creation of a „savior sibling“ through Pre-Implantation Genetic Diagnosis (PGD) and Human Leukocyte Antigen (HLA) tissue-typing, the reality of birthing a healthy child to become a “savior” for an existing, older, sick sibling is very much possible. The genome editing tool, CRISPR/Cas9 emerged in 2012, and has been heralded as „the most important discovery in the 21st century“. In the meantime, the global problem of infertility also translates into the success and further emergence of newer reproductive technologies, and with this precious realization, the need to also ensure the best health of the future child. Despite continuing debates on the ethical, legal and social implications (ELSI) of these technologies, I posit that it was only recently that these issues were forced to the foreground and propelled a reinvigorated and reawakened discourse.



In November 2018, at the Second International Summit on Human Genome Editing in Hong Kong, Chinese scientist, Dr. He Jiankui, shocked the summit by revealing that he had secretly edited (allegedly) the genes of twin embryos using the CRISPR/Cas9 technology. Not only were the twin girls successfully birthed, but the modifications made to their genes would carry on to their future generations. This is known as germ line genetic modification, an alteration that so drastically changes the fabric of DNA, that the international community of the summit, in its First International Summit on Human Genome Editing in 2015, unequivocally agreed to a self-imposed moratorium on germ-line modification. Beyond the spread of the wildfire-like news of Dr. He's claims, and still-incomplete investigation into the matter by relevant authorities (including the Chinese government), the international community clamored to hold on to the last vestiges of strong moral and ethical reasoning to re-emphasize an urgent need for action. Responding to this incident, in December 2018, the World Health Organization brought together a panel of international experts to begin working on „developing global standards for governance and oversight of human genome editing„.

Why was Dr. He's claims problematic? Beyond these news, and the surrounding ELSIs, my focus in this article is on the role of the family. Specifically, I highlight the role of prospective parents in the reprobogenetics phenomena, that I believe to be one of the factors that has culminated in genome editing experimentation on pre-implantation embryos in this manner. In my book, *Comparative Legal Frameworks for Pre-Implantation Embryonic Genetic Interventions*, I argue that reprobogenetics as a phenomenon has evolved through the visibility of infertility discourse and the access to newer reproductive technologies that appear to alleviate the global issues of infertility. In doing so, the effects from such availability of technologies, namely the embryo selection component, imparts upon prospective parents to select the best possible future child, leveraging on fertility practices and a new form of „liberal eugenics“.

“Liberal eugenics” has been so termed because the pejorative and offending elements of state-sanctioned hegemony of its citizens is no longer present. Instead, the decision to select genetic traits (if any) has been transferred to prospective parents. Scholars argue that because of this, then „the family is the level of implementation“. Although this may be viewed as a vindication of privacy, reproductive liberty and autonomy in concert with the universal principles of the human rights corpus, I argue that the presentation of this familial (parental) autonomy is a fallacy, that has been cloaked in seemingly more acceptable terms. First, I posit that parental autonomy in making decisions relating to genetic modifications (especially if these modifications purport to enhance, as opposed to providing therapeutic effect for a serious genetic illness) of their future offspring cannot be completely value-free. Secondly, I argue that this autonomous power in favor of parents provides a false sense of security and in fact, contributes to the extension of power of societal structures. Thirdly, I recall Foucault's discourse on the existence of power relations in every human interaction; namely „bio-power“, and politicization of the human body by subjugation through social and covertly political controls.

This is not to say that I am blatantly opposed to all forms of parental autonomy in making reproductive genetic decisions for their children. What I am opposed to, however, is a wholesale, free-for-all, unfettered power of autonomy that is unregulated, and fails to consider the unintended and perhaps, as yet, unidentified, future consequences of genomic alteration on the child. The equivalent possibilities of a future „genetic supermarket“ for future offspring, and the debates on parents' moral responsibility in „procreative beneficence“, as laudable as they may seem in fulfilled recognition of reproductive autonomy, do not, in my view, contribute to the resolution of current legal and ethical debates on controversial uses of new and emerging technologies. I put forward that democratic innovations like these, no matter how advantageous they may be to humankind, must be balanced against a social movement of a non-radical nature in the interest of enlightened medical discourse.

With our entry into a new age of industrialization, advancement and progress in reproductive biomedical innovations also simultaneously allows a progression of choice by parents, over bodies and reproduction. That the future of reproductive life may begin in a petri-dish and absent the physical causality through sexual intercourse, my view is that

the positioning of the law cannot be that of a passive bystander, but an active participant in the process to enhance and support procreative liberties whilst managing to invest in the important associations between ethics and legal legitimacy.

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