

Capstone Project Proposal

a. Designer Babies: A Threat to Neurodiversity or Solution to Heritable Disease

b. The issue of Designer Babies:

Science has advanced to a point that we can screen for certain abnormalities, genders and more using Genome Germline Editing. The FDA Cellular, Tissue and Gene Therapies Advisory Committee ruled in February 2015 that the 23&Me corporation could market their baby kit to screen for Bloom Syndrome (BS). The same corporation has the Family Traits Inheritable Calculator that allows one to pick and choose between certain traits for a child as well as screen for certain genetic disorders. Currently, Pre-implantation Genetic Diagnosis (PGD) is often used when assessing families at high risk for serious disorders. Sex selection is currently illegal in at least 36 countries, but not the U.S. (legal under the terms of 'family-balancing'). The FDA approved the original BS, but is yet to say anything about the FTIC.

Historical Context:

In 1927, Buck vs. Bell granted the state the right to sterilize people who were intellectually disabled or otherwise seemed unfit to be a parent. The aim was to 'purify' the genetic pool. Roe vs. Wade determined that the government couldn't interfere with a women's reproduction.

Looking at this under the Medical Model:

The Medical Model, which overall goal is to fix and abnormalities among children, would support genetic engineering of embryos to screen for 'healthy' babies that are free of any known genetic disease or genetic mutation.

Looking at this under the Disability Studies Model:

The concept of Designer Babies prevents neurodiversity and won't offer different genetic make up and different ways of thought into the gene pool. The DS Model approaches disabilities as differences and having individuals with disabilities generates more abstract ways of thinking and increases diversity in the genetic pool. By using such engineering and thereby eliminating the differences, would increase the stigma that already surrounds disabilities.

Where it is now:

No firm decision in the U.S. but there should be a collaborative, global effort to come to a consensus about genetic engineering in the creation of 'Designer Babies'.

c. With my project, I aim to delve further into topic that will no doubt change the field of Disability Studies. Genetic Engineering and the concept of Designer Babies is a much-debated topic and will become increasingly more so as the science behind it develops. This research paper will shed the light on the problem through the Disability Studies lens.