

Diversifying Syllabi 2017 Text Summary and Teaching Tips

SECTION ONE: to be completed by presenter (1-2 pages max.)

Article/Essay Title:

“A Case Study on CRISPR-Cas9 and the Deaf Community”

[Case can be accessed here: <http://deafbioethics.weebly.com/a-case-study.html>]

Author:

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Readability: Easy/Moderate/Difficult

This case is extremely accessible for different learning styles. It includes:

- Video ASL explanation of the case
- Auditory explanation of the case
- Written, English prose explaining the case (this is offered in multiple forms including a summary of the case, a transcript of the ASL video provided below the video, and captions on the video)

Thesis:

Key questions posed by the case:

- How should the government balance competing demands when it comes to reproductive liberties?
- What should be considered a “serious medical condition” or a “defect”?

[Note that the case site includes a number of other questions

<http://deafbioethics.weebly.com/questions.html>]

Key Definitions:

CRISPR-Cas9:

A gene editing technology that allows geneticists and medical researchers to edit parts of the gene by removing, adding, or altering sections of the human DNA sequence. CRISPR-Cas9 can eliminate perceived disease-causing genes and can be used before or during the early stages of a pregnancy

Human Fertilization and Embryology Act:

British legislation that prohibits the implantation of embryos, or donation of genetic material for anyone deemed to have a genetic difference that will result in a serious medical condition.

[Note: I’m not sure whether the “recent update” to the HFEA the case discusses is fictional or not. I haven’t found anything to suggest it’s real, however that could just be because I’m not looking in the right places...]

United Nations Declaration on the Rights of Indigenous People (UNDRIP):

“The Declaration sets out the individual and collective rights of indigenous peoples, as well as their rights to culture, identity, language, employment, health, education and other issues. It also "emphasizes the rights of indigenous peoples to maintain and strengthen their own institutions, cultures and traditions, and to pursue their development in keeping with their own needs and aspirations".^[6] It "prohibits discrimination against indigenous peoples", and it "promotes their full and effective participation in all matters that concern them and their right to remain distinct and to pursue their own visions of economic and social development"

Wikipedia contributors, "Declaration on the Rights of Indigenous Peoples," *Wikipedia, The Free Encyclopedia*, https://en.wikipedia.org/w/index.php?title=Declaration_on_the_Rights_of_Indigenous_Peoples&oldid=781840449 (accessed June 5, 2017).

Brief Summary:

[Note: There are some differences between the case presented in prose and the case presented in the video. Importantly, it's unclear what exactly the U.S. Bill prohibits. The inference in the written, prose version of the case is that it mandates CRISPR-CAS9 for embryos that will result in the child having a "serious medical condition," although this is not clearly stated and only implied. The video suggests that the Bill mandates CRISPR-CAS9 be used to ensure that "genes are free of defect."]

U.S. couple Vivian and Colin plan to have a baby together, and they receive genetic screening. Colin is Deaf. They learn that their baby will likely be born Deaf.

In the wake of HFEA (see definition above), the U.S. government is now considering enacting a reproductive law that mandates individuals who have health insurance use CRISPR-Cas9 if they are likely to have a child with a serious medical condition (see note above). If an individual considering having a baby does not want to use CRISPR-Cas9, their health insurance will be immediately revoked indefinitely.

Why enact this law?:

The national government reasons that, if parents do not want to uphold their duty of producing the healthiest babies, insurance companies and American taxpayers should not be obligated to fiscally support these "responsibility-shirking" parents.

What do Deaf activists say in response to this proposed law?:

National Association for the Deaf (NAD) has been working to block the proposed reproductive law. They rely on precedent laid out by the United Nations Declaration on the Rights of Indigenous People (UNDRIP), and argue that the deaf community shares similar features of indigenous communities.

1) They argue that Deaf parents should be granted reproductive liberty and legal protections to have deaf children, to protect Deaf culture.

2) The NAD further argues that Deaf people are entitled to free and unlimited access of CRISPR-Cas9 and any related genetic technologies to ensure Deaf births.

Possible Applications:

- Bioethics
- Intro Ethics
- Reproductive Ethics
- Philosophy of Disability

Complementary Texts/Resources:

- *Sound and Fury* (film)
- Heather Artinian, TEDxGeorgetown talk, <https://www.youtube.com/watch?v=jhm5OaXJVMQ>
- Isabel Karpin, "Choosing Disability: Preimplantation Genetic Diagnosis and Negative Enhancement"
- Melissa Seymour Fahmy, "On the Supposed Moral Harm of Selecting for Deafness"

- Ron Amundson, “Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics”
- Ron Amundson & Shari Tresky, “Bioethics and Disability Rights: Conflicting Values and Perspectives”

Possible Class Activities:

- Have students create similar websites for different case studies
- Discuss the similarities and differences between Deaf culture and indigenous cultures
- Have the students educate themselves about Deaf history and culture: e.g., <https://gallaudet.blackboard.com/bbcswebdav/institution/Deaf%20Eyes%20Exhibit/index.htm>