

# PHIL 106: BIOETHICS AND DISABILITY

## Professor:

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## Summer Online Course:

6/7/21 to 7/30/21

## COURSE DESCRIPTION

The field of bioethics emerged as a response to the not-so-distant history of eugenics in Britain, the United States, and Germany and to highly publicized and scandalous medical events in the 1950s onward, including the Tuskegee and Guatemala Experiments, rampant abuse and neglect under Jim Crow medical care, and the advent of technologies that could extend life beyond biological norms. Yet, bioethics is no longer one field (if it ever was), but many. It includes medical practitioners of every stripe, academics spanning the humanities and social sciences, policy and public health experts, and, increasingly, scientists whose research ranges across the life sciences. Practices of healthcare are at once scientific (finding empirical answers, saving lives) and political (concerned with resource distribution and bounded by legal and political restraints), and the vast array of work being done in bioethics represents this tension.

The questions posed by the field include: Is life sacred? What counts as life? Can we create life? Who owns life? How does one define need, harm, or risk? Whose lives matter and why? However, with the rise of the interdisciplinary field of disability studies in the '80s and disability rights activism since the '60s, it has become increasingly clear that all of these questions involve assumptions about ability and disability. Furthermore, discussions surrounding perennial bioethics topics such as euthanasia, physician-aid-in-dying, pre-implantation genetic diagnosis (PGD), prenatal testing, selective abortion, enhancement, and health care rationing all have a disproportionate impact on existing disability communities.

It is in this light that this class will provide an introduction to the field of bioethics through the lens of disability studies and philosophy of disability. It will cover traditional bioethical topics such as reproductive ethics, end of life care, health resource allocation, health disparities, and the ethics of enhancement and emerging technologies. Yet, unlike traditional bioethics classes, it will approach these issues by centering disability, asking questions such as: Is there a tension between the drive to cure vs. to care? Are end-of-life practices merely modern, liberal forms of eugenics? How does ableism impact biomedical

decision-making? How should the rise of disability rights activism impact how we think about issues such as medical rationing and crisis standards of care? Does disability pride have a place in the clinic? The course will also cover fundamental questions in disability studies, such as: What is the nature of disability? What counts as a disability? What is the meaning of accessibility? How is disability political?

## COURSE READINGS

All readings will be made available via Canvas.

## COURSE ASSIGNMENTS AND GRADING CRITERIA

### Graded Assignments

|                             |                  |
|-----------------------------|------------------|
| Participation               | 450 (45%)        |
| Short Paper (1)             | 250 (25%)        |
| <u>Final Research Paper</u> | <u>300 (30%)</u> |
| <b>TOTAL</b>                | <b>1000</b>      |

Participation is based on your engagement in the discussion board. Please look at Canvas under "Papers" for more details on the paper assignments.

### Grading Scheme

|                |
|----------------|
| 93 - 100 % = A |
| 90 - 92 % = A- |
| 87 - 89 % = B+ |
| 83 - 86 % = B  |
| 80 - 82 % = B- |
| 77 - 79 % = C+ |
| 73 - 76 % = C  |
| 70 - 72 % = C  |
| 67 - 69 % = D+ |
| 60 - 66 % = D  |
| Below 60 % = F |

## COURSE SCHEDULE

This course begins with an Orientation and is divided into 8 modules. Below is an outline describing the course structure. It is assumed that students will move through each module in sequential order.

## **ORIENTATION (Course Begins)**

The orientation module on Canvas will act as an introduction to and overview of the course.

## **MODULE 1**

*A Brief History of Medicine and Bioethics*

Readings:

- "A Short History of Modern Medicine and Disability" by Michael Rembis
- "Eugenics, Disability, and Bioethics" by Robert Wilson
- "A Critical History of Bioethics" by John Evans

## **MODULE 2**

*A Brief History of Disability Theory*

Readings:

- "Theories of Disability" by Joel Michael Reynolds
- "Ableism" by Talia Lewis [1 page]
- "The Spoon Theory" by Christine Miserandino [1 page]
- "The End of Identity Politics: On Disability as an Unstable Category" by Lennard J. Davis

## **MODULE 3**

*The Metaphysics of Disability*

Readings:

- "Making Up People" by Ian Hacking [10 pgs long]
- "What is Disease?" by Jackie Leach Scully [4 pgs long]
- "Human Nature: The Very Idea" by Tim Lewens [Stop reading once you hit section 4]
- "Valuing Disability, Causing Disability" by Elizabeth Barnes [Read only the following pages: 89-90, 94-104, & 109-113]

## **MODULE 4**

*Health, Illness, & Experience*

Readings:

- "The Lived Experiences of Disability" by S. Kay Toombs
- "Disability, Health, and Normal Function" by Elizabeth Barnes
- "Medicalization, 'Normal Function,' and The Definition of Health" by Quill [Rebecca] Kukla

Film: *Sins Invalid: An Unshamed Claim to Pride*

### **SHORT PAPER DUE**

#### **MODULE 5**

*Disability, Care, & Cure*

Readings:

- "The Truest Cyborg I Know" by Sara Hendren
- "Forever Small - The Strange Case of Ashley X" by Eva Feder Kittay
- "A Symmetrical View of Disability and Enhancement" by Stephen Campbell and David Wasserman

Film: *Fixed: The Science/Fiction of Human Enhancement*

#### **MODULE 6**

*Brain Death, MCS, & Disability*

Readings:

- "What Does It Mean to Die?" by Rachel Aviv
- "The Case of Jahi McMath: Race, Culture, and Medical Decision-Making" by Keisha Ray
- Selections from *Rights Come to Mind* by Joseph J. Fins

#### **MODULE 7**

*Aging, Dementia, & Disability*

Readings:

- "'Successful Aging,' Gerontological Theory and Neoliberalism: A Qualitative Critique" by Rubinstein and de Medeiros
- Selections from *Dementia Reimagined* by Tia Powell

- [OPTIONAL Extra Reading:] "Suffering and Generativity: Repairing Threats to Self in Old Age" by Kate de Medeiros

## MODULE 8

### *Physician Aid-in-Dying*

#### Readings:

- "Can there be a Disability Studies Theory of 'End-of-Life Autonomy?'" by Harold Braswell
- "The Future is Kid Stuff" by Lee Edelman (selection from *No Future: Queer Theory and the Death Drive*)
- Selections of "Suicidism: A New Theoretical Framework to Conceptualize Suicide from an Anti-Oppressive Perspective" by Alexandre Baril

Film: *The Sound of Metal*

## **FINAL RESEARCH PAPER DUE**

## COURSE POLICIES AND EXPECTATIONS

### Computer Requirements

- You will need access to a computer (Windows or Mac) and adequate Internet service to complete this course. Although you can use other devices such as smartphones and tablets for some online coursework, please note that some tools, such as Proctorio, do not work on tablets or smartphones.
- You will also need an internal or external microphone and camera to complete this course. While you can use any browser to access Canvas please note that some tools only work with certain browsers (e.g., Proctorio only works with Chrome).

The minimum requirements needed to use Canvas can be found in this [Canvas guide](#).

### Student Expectations

You are expected to complete all readings, assignments, and activities on time. Participation is essential to your success in this class. You are expected to actively participate in discussions with your peers and contribute to the group assignments. It is important to subscribe to the course discussion boards so that you receive notifications when new messages are posted. In order to get full credit for participation, you will have to complete all of your module assignments and quizzes on time.

## Time Expectations

Our online classes are designed to meet the same academic standards as our place-based (face-to-face) courses. This means the same level of participation, commitment, and academic rigor as a face-to-face class.

## Communication Expectations

### *Communication with Peers*

You will be expected to engage with your peers via the discussion board and other required tools on a regular basis.

### *Communication with Professor*

Please feel free to email me with your questions, concerns, and/or to schedule a time to meet over Zoom. When sending emails please remember the following guidelines: (1) always put the course number and topic of the message in the subject heading and (2) please compose your email professionally.

If you have *general* questions about assignments and course materials, please post these questions in the General Question Discussion Board Forum, which you can access by clicking Discussions in the course navigation menu. This is an open forum, and you are encouraged to give answers and help each other.

### *Netiquette Guidelines*

To promote the highest degree of education possible, we ask each student to respect the opinions and thoughts of other students and be courteous in the way that you choose to express yourself. Students should be respectful and considerate of all opinions.

In order for us to have meaningful discussions, we must learn to genuinely try to understand what others are saying and be open-minded about others' opinions. We must also be willing to have our views respectfully challenged. If you want to persuade someone to see things differently, it is much more effective to do so in a polite, non-threatening way rather than to do so antagonistically. Everyone has insights to offer based on his/her experiences, and we can all learn from each other. Civility is essential.

Speaking of being kind to one another, we are living through a pandemic. Everything is strange and many lives have been turned upside down. If you are having trouble (whether it be meeting a deadline, staying on top of things in the class, or whatever else), *please communicate with me*. I look forward to working together to come up with creative solutions.

## ACCESSIBILITY/ACOMMODATIONS

### Students with Disabilities

Under the Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973, individuals with disabilities have the right to specific accommodations. Some accommodations might include note takers, books on tape, extended time on assignments,

and interpreter services among others. Students are responsible before the start of classes for communicating their needs to the [Academic Resource Center](#), the office that oversees disability support services, (202-687-8354; [arc@georgetown.edu](mailto:arc@georgetown.edu); <https://academicsupport.georgetown.edu/disability/>) to allow time to review the documentation and make recommendations for appropriate accommodations. For the most current and up-to-date policy information, please refer to the [Georgetown University Academic Resource Center website](#). Students are highly encouraged to discuss the documentation and accommodation process with an Academic Resource Center administrator.

Having said all this, **access is a social justice issue**. Individual accommodations are more often than not a highly imperfect, second-best effort to address access. I am passionate about the principles of universal design in pedagogy, which include flexibility, equitability, tolerance for error and encouragement of response to it, and productive, albeit critical feedback loops. Syllabi and courses are designed with all students in mind, but we are not all the same. Your well-being and success in this course are very important to me, so please communicate with me, so that I can ensure you are getting as much from this course as possible.

### **Accessibility and Inclusion**

One of the central tenets of Georgetown's educational mission is *cura personalis*, a Latin phrase meaning "care of the whole person." Georgetown is committed to showing care and concern for each student by creating an inclusive and accessible learning environment that follows universal design principles to meet the needs of its diverse student body.

I am committed to creating a learning environment for my students that supports a diversity of thoughts, perspectives and experiences, and honors your identities (including along lines of race, gender, class, sexuality, religion, ability, etc.). For example, if your name or pronouns need to be corrected, please let me know early in the semester so that I can make the appropriate changes to my records.

## **ACADEMIC INTEGRITY**

Students at Georgetown University are expected to maintain the highest standards of academic and personal integrity. Although most Georgetown students conduct themselves in accordance with these standards, occasionally, there are students who violate the code of conduct. Cheating harms the University community in many ways. For example, honest students are frustrated by the unfairness of cheating that goes undetected and students who cheat can skew the grading curve in a class, resulting in lower grades for students who worked hard and did their own work.

Academic dishonesty in any form is a serious offense, and students found in violation are subject to academic penalties that include, but are not limited to failure of the course, termination from the program, and revocation of degrees already conferred. All students are expected to fully adhere to the policies and procedures of [Georgetown's Honor System](#) and to take the Honor Code Pledge.

## Honor Code Pledge

In pursuit of the high ideals and rigorous standards of academic life I commit myself to respect and to uphold the Georgetown University honor system; to live out a commitment to integrity in all my words and actions; to be honest in every academic endeavor; and to conduct myself honorably, as a responsible member of the Georgetown community as we live and work together; to live out the ideals of Georgetown University I commit myself to be a person for others in my daily life, respectful of difference and disagreement; To care for this venerable campus and all of those with whom I share it; and to fulfill in all ways the trust placed in me to carry on the Georgetown tradition.

## Plagiarism

Stealing someone else's work is a terminal offense in the workplace, and it will wreck your career in academia, too. Students are expected to work with integrity and honesty in all their assignments. The Georgetown University Honor System defines plagiarism as "the act of passing off as one's own the ideas or writings of another." More guidance is available through the [Gervase Programs](#). If you have any doubts about plagiarism, paraphrasing, and the need to credit, check out [Plagiarism.org](#).

All submissions must be your original work. Any submission suspected of plagiarism will be immediately referred to the Honor Council for investigation and possible adjudication. All students are expected to follow Georgetown's honor code unconditionally. If you have not done so, please read the honor code material located online at the [Honor Council website](#).

## SUPPORT SERVICES

Georgetown recognizes that COVID-19 has a significant impact on everyone in the Georgetown community. Georgetown offers a variety of support services for students that can be accessed online and has put together [this newsletter](#) which aims to provide you with information about well-being resources and virtual meetings that can connect you with mental health professionals on and off campus during this time. Below are some resources available to you:

- [Academic Resource Center](#)  
202-687-8354 | [arc@georgetown.edu](mailto:arc@georgetown.edu)
- [Counseling and Psychiatric Services](#)  
202-687-6985
- [Institutional Diversity, Equity & Affirmative Action \(IDEAA\)](#)  
(202) 687-4798

## Title IX/Sexual Misconduct

Georgetown University and its faculty are committed to supporting survivors and those impacted by sexual misconduct, which includes sexual assault, sexual harassment, relationship violence, and stalking. Georgetown requires faculty members, unless otherwise designated as confidential, to report all disclosures of sexual misconduct to the University Title IX Coordinator or a Deputy Title IX Coordinator. If you disclose an incident of sexual misconduct to a professor in or outside of the classroom (with the exception of disclosures in papers), that faculty member must report the incident to the Title IX Coordinator, or



Deputy Title IX Coordinator. The coordinator, will, in turn, reach out to the student to provide support, resources, and the option to meet. [Please note that the student is not required to meet with the Title IX coordinator.].

Please note that University policy requires faculty to report any disclosures about sexual misconduct to the Title IX Coordinator, whose role is to coordinate the University's response to sexual misconduct. Georgetown has a number of fully confidential professional resources who can provide support and assistance to survivors of sexual assault and other forms of sexual misconduct. These resources include:

- Jen Schweer, MA, LPC, Associate Director of Health Education Services for Sexual Assault Response and Prevention (202) 687-0323 | [jls242@georgetown.edu](mailto:jls242@georgetown.edu)
- Erica Shirley, Trauma Specialist, Counseling and Psychiatric Services (CAPS), (202) 687-6985 | [els54@georgetown.edu](mailto:els54@georgetown.edu)

More information about reporting options and resources can be found on [the Sexual Misconduct Website](#).

### **Title IX/Pregnancy and Parenting Accommodations**

Georgetown University is committed to creating an accessible and inclusive environment for pregnant and parenting students. Students may request adjustments based on general pregnancy needs or accommodations based on a pregnancy-related complication. Specific adjustments will be handled on a case by case basis and will depend on medical needs and academic requirements. Students seeking a pregnancy adjustment or accommodation should follow the process laid out on the [Title IX website](#).

Discrimination based on sex, including sexual misconduct and discrimination based on pregnancy or parenting status, subverts the University's mission and threatens permanent damage to the educational experience, careers, and well-being of students, faculty, and staff.

### **Georgetown Library**

If you have a question for a librarian you can go to their ["Ask Us"](#) page where you will have the option to chat online, send an email, or schedule a Zoom appointment to discuss a research topic, develop a search strategy, or examine resources for projects and papers. Librarians offer an overview of and in-depth assistance with important resources for senior or master's theses, dissertations, papers and other types of research. This service is available to currently enrolled students who need assistance with Georgetown-assigned projects and papers. Please review the [Services & Resources Guide for Online Students](#) for additional information.

### **eResources**

Students enrolled in courses have access to the University Library System's eResources, including 500+ research databases, 1.5+ million ebooks, and thousands of periodicals and other multimedia files (films, webinars, music, and images). You can access these resources through the [Library's Homepage](#) by using your NetID and password.

## Learning Resources

Georgetown offers a host of [learning resources](#) to its students. Two that you might find particularly helpful in this course are the [Writing Center](#) and [Refworks](#).

- [The Writing Center](#) offers peer tutoring by trained graduate and undergraduate students who can assist you at any point in the writing process. They help at any stage of your writing process, from brainstorming to revision. Tutors can offer advice on thesis development, use of evidence, organization, flow, sentence structure, grammar, and more. The Writing Center will not proofread or edit papers; rather, they will help to improve your proofreading and editing skills to become a better writer. Appointments can be booked online through their website.
- [Refworks](#) is an online research management tool that aids in organizing, storing, and presenting citation sources for papers and projects. I think [Zotero](#) is actually better, but it doesn't take long to get a feel for each and see what you think.

## Technical Support

All students have 24/7 access to Canvas technical support 24 hours a day, 7 days a week, including live chat and a support hotline at 855-338-2770. Use the 'Help' icon in the lower left of your Canvas window to view all available support and feedback options. If you're looking for help on a specific feature, check out the [Canvas Student Guide](#).

## PRIVACY, JOURNALISTIC ETHICS, AND INTELLECTUAL PROPERTY

To promote learning, this course encourages open inquiry and discussion by and among course participants in an atmosphere of mutual respect and candor. Students must be able to engage in class discussion freely, without fear that their conversations and personally-held views will be shared with the general public. Accordingly, **the course materials and discussions by or among course participants cannot be recorded or reported on or distributed to anyone outside of the class without the clear and explicit consent of all individuals involved (including the instructor).**

## SYLLABUS THANK YOUS

Teaching and research is carried out in community with others. I am very grateful for fantastic colleagues and intellectual friends across the globe, and I would like to thank the following people in particular for either explicit suggestions (via conversation or their own syllabi) or for more general influences on the content, form, and approach to this course: Rosemarie Garland-Thomson, Eva Kittay, Lauren Guilmette, Jennifer Scuro, Christine Wieseler, Jennifer Sarrett, Erik Parens, Nick Evans, Alison Reiheld, Meredith Schwartz, David Pena-Guzman, and Quill Kukla.