

Ethics and Disability

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| Class Schedule: M W 11:00-12:15 |
| Class Location: 194 Mercer, Room 305 |
| Semester and Year: Spring 2019 |

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| Professor: Jordan MacKenzie | Office: 715/719 Broadway, Rm. 1225 |
| Phone: (919) 667-4001  | Office Hours: Tuesday 10-11 and by appointment |
| Email: jordan.mackenzie@nyu.edu |  |

**COURSE DESCRIPTION:**

This course is a survey of ethical, political, and metaphysical issues relating to disability—issues that are of central importance in the biomedical sciences and health care. Foundational issues addressed include: What is disability? Is disability inherently bad or instead neutral? How do people with a disability describe their life, relationships, and experiences? Is it permissible to intentionally cause or prevent disability? What is the relationship between disability and well-being? Other topics include the ethics of genetic screening and selection, procreative responsibilities, disability and justice, the moral status of people with severe cognitive disabilities, and the ethics of care and dependency. Gaining greater clarity regarding these philosophical and ethical questions is of vital importance as we move forward as an increasingly diverse and pluralistic society.

**COURSE LEARNING OBJECTIVES AND COMPONENTS:**

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| **Learning Objective** | **Course component**  |
| By the end of the course, students will learn how to…1. Describe the differences between medical and social models of disability, and how disability can be part of one’s identity. | Lesson: Jan 28, Jan 30, Feb 4, Feb 6, April 17, April 22, April 24Assignment: Essay 1 |
| 2. Explain some of the key ethical dilemmas related to disability and procreation. | Lesson: Feb 18, Feb 20, Feb 27 |
| 3. Describe key philosophical views on the nature of justice, and analyze how these views can be used to explain the obligations society has to accommodate disabilities.  | Lesson: April 1, April 3, April 8, April 10Assignment: Essay 2 |
| 4. Provide an ethical analysis of real-world cases related to themes in this course. | Lesson: Feb 27, Mar 4, Mar 6, April 15Assignment: Ethics Case Study Presentation |
| 5. Describe key philosophical arguments related disability and end of life ethical issues | Lesson: April 29, May 1Assignment: Take home exam |

**PRE-REQUISITES:**

No Pre-requisites.

**COURSE REQUIREMENTS AND EXPECTATIONS:**

**Attendance**: Regular and timely attendance is required. Material will be covered in class that is not covered in the readings. Each student is allowed two unexcused absences; each subsequent unexcused absence will result in a 1/3 letter grade reduction for the course.

**Participation:** Although attendance is essential to a successful performance in this class, it is not sufficient. It is important that you come to class prepared to discuss and ask questions about the assigned readings. You can also participate by attending office hours. I expect you to contribute to in-class discussion in a substantive way at least once a week during the semester. I will keep track of participation during class. Failure to participate at least once a week will result in a 1/4 letter grade reduction (-2.5 points) for the course; failure to participate at all will result in an additional 1/4 letter grade reduction (total -5 points) for the course.

I recognize that some students may have difficulties fulfilling the participation requirement in this course through class discussion. If you feel that you may be one of these students, I would be happy to make alternative arrangements with you (e.g. substituting participation in office hours or via email for in-class discussion). However, it is essential that you contact me early in the semester (e.g. by week 2) to make these arrangements).

**Timely completion of readings**: The readings require careful study. It’s important that you read *actively*—try to summarize key ideas and arguments, and try to think of objections. Don’t hesitate to fill the margins with questions and comments, which you can return to later.

**Content and Decorum:**

* We will be discussing many controversial issues in this course, and challenging our beliefs throughout. Students should expect to discuss topics like: mental illness, pain, sexuality, sex, race, discrimination, oppression etc. I will not be giving content warnings in advance of specific classes. If you are concerned about course content, please come speak to me.
* A respectful discussion environment is absolutely essential in this course. This requires, among other things, that we all:
	+ Listen actively when others are speaking
	+ Avoid making derogatory comments or using derogatory language
	+ Call class participants by their preferred names and pronouns
* Students who fail to respect this decorum policy may be asked to leave

**Technology Policy:** Laptops are allowed, but strongly discouraged. Cell phones must be turned off during class except during emergencies.

**STATEMENT OF ACADEMIC INTEGRITY:**

The NYU College of Global Public Health values both open inquiry and academic integrity. Students in the program are expected to follow standards of excellence set forth by New York University. Such standards include respect, honesty and responsibility. The CGPH does not tolerate violations to academic integrity including:

* Plagiarism
* Cheating on an exam
* Submitting your own work toward requirements in more than one course without prior approval from the instructor
* Collaborating with other students for work expected to be completed individually
* Giving your work to another student to submit as his/her own
* Purchasing or using papers or work online or from a commercial firm and presenting it as your own work

Students are expected to familiarize themselves with the CGPH and University’s policy on academic integrity as they will be expected to adhere to such policies at all times – as a student and an alumni of New York University.

Plagiarism

Plagiarism, whether intended or not, is not tolerated in the CGPH. Plagiarism involves presenting ideas and/or words without acknowledging the source and includes any of the following acts:

* Using a phrase, sentence, or passage from another writer's work without using quotation marks
* Paraphrasing a passage from another writer's work without attribution
* Presenting facts, ideas, or written text gathered or downloaded from the Internet as your own
* Submitting another student's work with your name on it
* Submitting your own work toward requirements in more than one course without prior approval from the instructor
* Purchasing a paper or "research" from a term paper mill.

Students in the CGPH and CGPH courses are responsible for understanding what constitutes plagiarism. Students are encouraged to discuss specific questions with faculty instructors and to utilize the many resources available at New York University.

Disciplinary Sanctions

When a professor suspects cheating, plagiarism, and/or other forms of academic dishonesty, appropriate disciplinary action is as follows:

* The Professor will meet with the student to discuss, and present evidence for the particular violation, giving the student opportunity to refute or deny the charge(s).
* If the Professor confirms that violation(s), he/she, in consultation with the Chairperson/Program Director may take any of the following actions:

	+ Allow the student to redo the assignment
	+ Lower the grade for the work in question
	+ Assign a grade of F for the work in question
	+ Assign a grade of F for the course
	+ Recommend dismissal

Once an action(s) is taken, the Professor will inform the Chairperson/Program Director and inform the student in writing, instructing the student to schedule an appointment with the Senior Associate Dean for Academic Affairs, as a final step. The student has the right to appeal the action taken in accordance with the GPH Student Complaint Procedure.

**STUDENTS WITH DISABILITIES:**

Students with disabilities should contact the Moses Center for Students with Disabilities regarding the resources available to them, and to determine what classroom accommodations should be made available. More information about the Moses Center can be found here. must appear on the syllabus. Information about the center can be found here: <https://www.nyu.edu/life/safety-health-wellness/students-with-disabilities.html>. Students requesting accommodation must obtain a letter from the Moses Center to provide to me as early in the semester as possible.

**ASSIGNMENTS:**

Short Survey Assignment: Tomorrow afternoon, a short survey will be posted on NYU Classes. You will be asked questions about what topics you’d like to see covered in the course, your reasons for taking the class etc. Please fill in this survey and submit it to me by Wednesday, January 29, 2019.

Paper Assignments: Students will complete two papers based on assigned topics. Papers should be argumentative. This means that you must take up some sort of *stance* in response to the prompt, and then defend that stance against objections.

Students have the option of re-writing papers in this course. Rewritten papers are due **one week** after the original paper is handed back. Students will then receive a grade that is an average of the original grade and the rewritten grade. I will not provide feedback on the rewrite.

Case Study Presentation: Working in groups of 4, students will select a real world case engaging with themes from this course. They will then complete and present an ethical analysis of the case to the class. To complete this assignment, students must:

1. Find a case and send it to me for approval in advance of the presentation date.
2. Create a presentation that:
	1. Summarizes the main facts of the case.
	2. Identifies the morally significant features of the case, as well as the key ethical dilemmas raised by the case.
	3. Makes an ethical determination about what ought to be done in the case.
	4. Consider and respond to objections that someone might have about the ethical determination that they have made.

Presentations should be approximately 15 minutes in length. Crucially, this presentation must be *engaging* in some way. Students will be graded not only on the strength of their ethical reasoning, but also on their ability to communicate information to their peers in an informative and engaging manner. Students should, for instance, try to incorporate a class participation activity into their presentation. I will provide more details about this assignment later in the term.

Final Take Home Exam:

**Assignment Submission**: please bring a hard copy of Essay 1 and Essay 2 to class on their due date. The survey assignment and final take-home exam will be submitted electronically.

**Extensions**: I am happy to grant extensions with advanced notice. If you require an extension on any assignment (with the exception of the Ethics Case Presentation, which will only be rescheduled in extreme circumstances at my discretion), please email me at least 24 hours before the assignment is due. You do not need to provide any explanation if you are requesting an extension of 48 hours or less. Longer extension requests will require appropriate explanation and/or documentation.

**Anonymous grading**: to facilitate anonymous grading, please do not include your name anywhere on your assignments, with the exception of the introductory survey assignment. Use your student number (i.e. N-#) instead.

**GRADING RUBRIC:**

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| **Item:** | **Percentage or Points:** |
| We Attendance and Active Participation | **12** |
| SSurvey Survey Assignment | **3** |
| Essay 1 | **20** |
| Essay 2 | **25** |
| Ethics Case Study Presentation | **15** |
| Final Take-Home Essay  | **25** |
| **Total** | **100** |

**GRADING SCALE:**

A: 93-100 C+: 77-79

A-: 90-92 C: 73-76

B+: 87-89 C-: 70-72

B: 83-86 D+: 67-69

B-: 80-82 D: 60-66

F: <60

**NYU CLASSES:**

NYU Classes will be used extensively throughout the semester for assignments, announcements, and communication. NYU Classes is accessible through at <https://home.nyu.edu/academics>

**COURSE OUTLINE:**

**NOTE: This course outline is not a contract. Readings and topics may change throughout the semester.**

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| **Date** | **Topics** | **Readings** | **Assignments Due** |
| Week 1-Jan 28 | **Introduction** | No Readings | **Survey Assignment Distributed** |
| Jan 30 | **Defining Disability** | Wendell, *The Rejected Body*, Chapters 1-2 (Focus on Chpt 2) | **Survey Assignment Due** |
| Week 2-Feb 4 | **Intro to Moral Theory** | Timmons, *Moral Theory* (Excerpts) |  |
| Feb 6 | **Disability as a Mere Difference?**  | Bogner, “Is Disability Mere Difference?”Note: This class will also focus on the basics of philosophical argument reconstruction |  |
| Week 3-Feb 11 | **The Ethics of Genetic Screening** | *CANCELLED* | **Essay 1 Prompt Distributed** |
| Feb 13 | **The Ethics of Genetic Screening** | ErikParens and Adrienne Asch, ‘The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations’, *The Hastings Center* |  |
| Week 4- Feb 18 | **President’s Day—No Class** |  |  |
| Feb 20 | **The Ethics of Genetic Screening** | J. Malek, “Deciding Against Disability,” *Journal of Medical Ethics* |  |
| Week 5-Feb 25 | **Case Study: Deafness** | Spriggs, “Lesbian Couple Create Child Who Is Deaf Like Them,” *Journal of Medical Ethics*Levy, “Deafness, Culture, and Choice,” *Journal of Medical Ethics*Robert Crouch, “Letting the Deaf be Deaf,” *Hastings Center Report* |  |
| Feb 27 | **The Ashley Treatment** | S. Matthew Liao, Julian Savulescu, Mark Sheehan, “The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making,” *The Hastings Center Report* | **Essay 1 Due** |
| Week 6-Mar 4 |  | “SNOW” DAY! |  |
| Mar 6 | **Disability and Respect** | Adam Cureton, “Offensive Beneficence” |  |
| Week 7-Mar 11 | **Deciding for Others** | J. Anderson and W. Lux, “Accurate Self-Assessment, Autonomous Ignorance, and the Appreciation of Disability,” *Philosophy, Psychiatry, and Psychology* |  |
| Mar 13 | **Disability and Justice: Equality** | Jonathan Wolff, “Disability Among Equals” in *Disability and Disadvantage**AND**Ethics Case Study Presentations* | **Case Study Topics Submitted**  |
| Mar 18 | **SPRING BREAK**  |
| Mar 20 | **SPRING BREAK**  |
| Week 8-Mar 25 | **Disability and Justice: Equality** | LindaBarclay, ‘Disability, Respect and Justice’, *Journal of Applied Philosophy**AND**Ethics Case Study Presentations* |  |
| Mar 27 | **Disability and Justice: Healthcare Resource Allocation** | Dan Brock, ‘Justice and the ADA: Does Prioritizing and Rationing Health Care Discriminate against the Disabled?’, S*ocial Philosophy and Policy* | **Case Study Assignment Due****Essay 2 Prompts Distributed** |
| Week 9-Apr 1 | **Disability and Justice: Healthcare Resource Allocation** | Dominic Wilkinson and Julian Savulescu, “Prioritization and Parity: Which Disabled Newborn Infants Should Be Candidates for Scarce Life-Saving Treatment?” *Oxford Handbook of Philosophy and Disability* |  |
| Apr 3 | **Mental Illness** | Sisti et al. “Defining Mental Illness” |  |
| Week 10-Apr 8 | **Mental Illness** | Belluck, “First Digital Pill”Sisti et. al. “Improving Long-Term Psychiatric Care: Bring Back the Asylum” |  |
| Apr 10 | **Disability and Accommodation** | Istvan, “In the Transhuminist Age, We Should Be Repairing Disabilities, Not Sidewalks”Eveleth “The Exoskeleton’s Hidden Burden” |  |
| Week 11-Apr 15 | **BIID** | Bayne and Levy, “Amputees by Choice,” *Journal of Applied Philosophy* | **Essay 2 Due** |
| Apr 17 | **Disability and Testimony** | Barnes, Chapter 4: “Taking Their Word for It” |  |
| Week 12-Apr 22 | **Disability and Testimony** | GaryAlbrecht and Patrick Devlieger, ‘The Disability Paradox: High Quality of Life Against All Odds,’ *Social Science and Medicine*Sara Goering, ‘“You say you’re happy, but …”: Contested Quality of Life Judgments in Bioethics and Disability Studies’, *Journal of Bioethical Inquiry* |  |
| Apr 24 | **Disability and Testimony** | Crossley, “Parental Autonomy, Children with Disabilities, and Horizontal Identities,” *Oxford Handbook of Philosophy and Disability* |  |
| Week 13-Apr 29 | **Disability and End of Life Issues** | Danny Scoccia, “The Disability Case Against Assisted Dying,” The Disability Case Against Assisted Dying | **Final Take Home Exam Questions Distributed** |
| May 1 | **Disability and End of Life Issues** | Lennard Davis, “A Disability Studies Case for Physician-Assisted Suicide” *The End of Normal* |  |
| Week 14-May 6 | **Disability and Sex** | J.M. Appel, “Sex Rights for the Disabled?” *Journal of Medical Ethics*E. Di Nucci, “Sexual Rights and Disability” *Journal of Medical Ethics* |  |
| May 8 | **Disability and Sex** | A. Schriempf, “(Re)fusing the Amputated Body,” *Hypatia.*   |  |
| Week 15-May 13 | **Disability and Media Representation** | TBD |  |
| May 16 | ***Final Take-Home Exam Due***  |