

BETH 320/420: Disability Bioethics

Faculty

Dr. Laura Guidry-Grimes

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Office hours by appointment

Class location and time

Location: Wolstein Research Building,
WRB 1217

When: Tues/Thurs, 2:30-3:45

Teaching Assistant

Gargi Pandey, MPH

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Office hours by appointment –

Zoom or Bioethics dept/Sears

Tower room TA224

** For all email correspondence regarding the course (except for grade appeals or other sensitive matters), please contact both Dr. Guidry-Grimes and Gargi.*

COURSE DESCRIPTION

What values and assumptions underlie our conceptualizations of disability? What can we learn from the lived experiences of disabled people and communities? How should these insights inform fundamental concepts, priorities, and analyses in bioethics? Even though developments in medicine, clinical research, and public health often disproportionately impact people with disabilities, disabled people have been systemically marginalized within these fields and within bioethical discourse. This course introduces students to the distinctive approach known as disability bioethics. Disability bioethics is characterized by 1) rejection of biomedical interpretations of disability, 2) methodological primacy of the perspectives of disabled persons, and 3) anti-ableism. We will explore this theoretical lens and its application to a range of issues, such as biomedical technology, guardianship for healthcare decisions, futility judgments, and public health emergencies.

PREREQUISITES

There are no prerequisites. This course is intended for undergraduate and graduate students, as well as students in the health professions.

REQUIRED TEXT

The Disability Bioethics Reader, edited by Joel Michael Reynolds and Christine Wieseler (NY: Routledge, 2022).

All other materials will be provided through Canvas.

LEARNING OBJECTIVES

By the end of this course, students will be able to

1. Describe the distinctive aspects of disability bioethics as an approach to bioethics;
2. Discuss insights from first-person testimony of diverse disabled people that should inform bioethical analysis;
3. Analyze key topics and debates in bioethics through a disability bioethics lens; and
4. Analyze the ways in which forms of human difference shape a person’s experiences of and perspectives on contemporary and historical issues and/or how one’s actions could have disparate impacts on different people.

COURSE SCHEDULE

DATE	TOPIC	PREPARATION
Tues 1.16	Introductions	

<p>Thurs 1.18</p>	<p>Fraught Relationship: Bioethics and Disability</p>	<p><u><i>*Choose two:</i></u></p> <p>“If Not Now, Then When? Taking Disability Seriously in Bioethics” by Debjani Mukherjee, et al.</p> <p>“Disability Bioethics: Introduction to <i>The Disability Bioethics Reader</i>” by Joel Michael Reynolds and Christine Wieseler</p> <p>“Why Bioethics Needs a Disability Moral Psychology” by Joseph A. Stramondo</p> <p>“Disability: An Agenda for Bioethics” by Mark Kuczewski</p> <p><i>Disability Bioethics: Moral Bodies, Moral Difference</i> (excerpt) by Jackie Leach Scully</p>
<p>UNIT I: LIVED EXPERIENCES OF DISABILITY</p>		
<p>Tues 1.23</p>	<p>Health Care <i>Guest speaker:</i> <i>Dr. Katie Savin</i></p>	<p>“My ICU Summer” by Alice Wong</p> <p>“Taking Charge of My Story as a Cancer Patient at the Hospital Where I Work” by Diana Cejas</p> <p>“I Use a Wheelchair. And Yes, I’m Your Doctor.” by Cheri A. Blauwet</p> <p>“An Open Letter to my Health Insurance Company” by Jenny Lawson</p> <p><i>In-class exercise: Narrative mapping</i></p>
<p>Thurs 1.25</p>	<p>Recovery and resilience</p>	<p>“In My Chronic Illness, I Found a Deeper Meaning” by Elliot Kukla</p> <p>“Nurturing Black Disabled Joy” by Keah Brown</p>

		<p>“My Supercharged, Tricked Out, Bluetooth Wheelchair Life Force” by Katie Savin</p> <p>“Important Steps to Recovery with Voices” by Marius Romme</p> <p><i>In-class exercise: Narrative mapping</i></p>
Tues 1.30	Advocacy	In-class viewing: <i>Crip Camp</i>
Thurs 2.1	Advocacy	<p>In-class viewing: <i>Crip Camp</i></p> <p><i>In-class exercise: Narrative mapping</i></p>
UNIT II: WHAT DOES IT MEAN TO BE DISABLED?		
Tues 2.6	Foundations	<p><i>Demystifying Disability</i>, Chapter 1 by Emily Ladau</p> <p>“Theories of Disability” by Joel Michael Reynolds (DBR Ch. 3)</p>
Thurs 2.8	History and context	<p>“A Short History of Modern Medicine and Disability” by Michael Rembis (DBR Ch. 1)</p> <p>“Eugenics, Disability, and Bioethics” by Robert A. Wilson (DBR Ch. 2)</p> <p>*DUE by 5:00 pm on Friday, 2.9: Analytic Narrative Map & Reflection 1</p>
Tues 2.13	Bioethical theorizing	<p>“Disability Bioethics: From Theory to Practice” by Rosemarie Garland-Thomson (DBR Ch. 6)</p> <p>“Disability and the Definition of Health” by Sean Aas (DBR Ch. 7)</p>
Thurs 2.15	<i>Class canceled due to illness</i>	
Tues 2.20	<p>Aging</p> <p><i>Guest speaker: Dr. Erin Lamb</i></p>	“Disability and Age Studies: Obstacles and Opportunities” by Erin Gentry Lamb (DBR Ch. 16)

		<p>“Bioethical Issues in Dementia and Alzheimer’s Disease” by Tia Powell (DBR Ch. 19)</p> <p>“Why I Hope to Die at 75” by Ezekiel Emanuel</p>
Thurs 2.22	<p>Mental health and psychiatry</p> <p><i>Guest speakers:</i> <i>Dr. Julia Knopes & Dr. Lindsey Grubbs</i></p>	<p>“Defining Mental Illness and Psychiatric Disability” by Laura Guidry-Grimes (DBR Ch. 26)</p> <p>“Inconvenient Complications to Patient Choice and Psychiatric Detention: An Auto-ethnographic Account of Mad Carework” by Erica Hua Fletcher (DBR Ch. 28)</p> <p>*DUE by 11:59 pm on Sunday, 2.25: Reflection 2</p>
UNIT III: MEDICINE AND HEALTHCARE		
Tues 2.27	Access and attitudes	<p>“Improving Access within the Clinic” by Nicole D. Agaronnik and Lisa I. Iezzoni (DBR Ch. 33)</p> <p>“Physicians’ Perceptions of People with Disability and Their Health Care” by Lisa I. Iezzoni, et al.</p>
Thurs 2.29	Genetics and an open future	<p>“Genetic Dilemmas and the Child’s Right to an Open Future” by Dena S. Davis</p> <p>“Disability and the Damaging Master Narrative of an Open Future” by Joseph A. Stramondo</p>
Tues 3.5	Race and racism	<p>“What It’s Like to Be Black and Disabled in America” by Shalene Gupta</p> <p>“Disability Bioethics and Race” by Andrea J. Pitts (DBR Ch. 22)</p>
UNIT IV: AGENCY		
Thurs 3.7	(Inter)dependence	<p>“Disability and Vulnerability: On Bodies, Dependence, and Power” by Jackie Leach Scully</p> <p>“Deciding with Others: Interdependent Decision-Making” by Emily A. Largent, et al.</p>

		*DUE by 5:00 pm on Sunday, 3.10: Reflection 3
SPRING BREAK		
Tues 3.19	Intellectual disability	<p>“Chapter 1: Introduction to ID/DD, Guardianship, and Alternatives” by NCD</p> <p>“Chapter 6: Other Stakeholder Experiences with the Guardianship System and Alternatives” by NCD</p>
Thurs 3.21	Psychiatric disability	<p>“Overcoming Obstacles to Shared Mental Health Decision Making” by Laura Guidry-Grimes</p> <p>“Epistemic Injustice in Psychiatry” by Paul Crichton, et al.</p> <p>“Medication Refusal in Schizophrenia: Preventive and Reactive Ethical Considerations” by James Sabin</p>
UNIT V: QUALITY OF LIFE, GOODS, AND HARMS		
Tues 3.26	Quality of life judgments	<p>“‘You Say You’re Happy, but...’: Contested Quality of Life Judgments in Bioethics and Disability Studies” by Sara Goering</p> <p>“Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics” by Ron Amundson (DBR Ch. 13)</p>
Thurs 3.28	<p>Quality of life judgments</p> <p><i>Guest speaker: Dr. Joel Michael Reynolds</i></p>	<p>“Unspeakable Conversations” by Harriet McBryde Johnson</p> <p>“From the Eyeball Test to the Algorithm – Quality of Life, Disability Status, and Clinical Decision Making in Surgery” by Charles E. Binkley, Joel Michael Reynolds, and Andrew Shuman</p>

		*DUE by 5:00 pm on Friday 3.29: Case Analysis 1
Tues 4.2	Futility judgments	<i>Medical Futility and Disability Bias</i> (excerpts) by NCD
Thurs 4.4	Reproduction Join via Zoom <i>Guest speaker:</i> <i>Dr. Liz Bowen</i>	“Abortion, Disability Rights, and Reproductive Justice” by Elizabeth Dietz (DBR Ch. 9) “The End of <i>Roe v. Wade</i> Will Be a Nightmare for Disabled Americans” by Liz Bowen
Tues 4.9	Ashley X Join via Zoom <i>Guest speaker:</i> <i>Dr. Christine Wieseler</i>	“Should Parents of Children with Severe Disabilities Be Allowed to Stop Their Growth?” by Genevieve Field “Disability Bioethics, Ashley X, and Disability Justice for People with Cognitive Impairments” by Christine Wieseler (DBR Ch. 29)
Thurs 4.11	End of Life	“Misuses of ‘Quality of Life’ Judgments in End-of-Life Care” by Devan Stahl “Between ‘Aid in Dying’ and ‘Assisted Suicide’: Disability Bioethics and the Right to Die” by Harold Braswell (DBR Ch. 20) *DUE by 5:00 pm on Friday 4.12: Case Analysis 2
UNIT VI: PUBLIC HEALTH EMERGENCIES		
Tues 4.16	Pandemic	<i>The Impact of COVID-19 on People with Disabilities</i> (excerpt) by NCD “Death, Pandemic, and Intersectionality: What the Failures in an End-of-Life Case Can Teach about Structural Justice” by Yolonda Wilson (DBR Ch. 17) *DUE by 5:00 pm on Tuesday 4.16: Send both the professor and TA your idea for a final project.

Thurs 4.18	Pandemic	<p>“Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care” by Laura Guidry-Grimes, et al.</p> <p>“I’m Disabled and Need a Ventilator to Live. Am I Expendable during This Pandemic?” by Alice Wong</p> <p>*DUE FOR GRADUATE STUDENTS by 5 pm on Monday 4.22: Triage Protocol Analysis</p>
Tues 4.23	Student Presentations	<p>*In-class: GRADUATE STUDENTS to present their final project ideas</p>
Thurs 4.25	Global warming and natural disasters	<p>“Global Disability Justice in Climate Disasters: Mobilizing People with Disabilities as Change Agents” by Alina Engelman, et al.</p> <p>“Disability after Disaster: Reflections from a Disabled First Responder” with Germán Pardi and Julia Watts Belser</p> <p>“Climate Action,” Ep. 87 of <i>Disability Visibility</i> Podcast with Kera Sherwood-O’Regan</p>
Tues 5.7	FINAL PROJECT TO BE SUBMITTED	

ASSESSMENT AND GRADING

The below table provides an outline of each form of assessment for the course, as well as how much each is worth. More detailed instructions and rubrics will be posted on Canvas, which can be made more accessible as requested. All assignments are individual assignments unless noted otherwise.

The professor will grade all assignments for Ph.D. students. The teaching assistant and professor will work together on grading for all other students.

Note for all written assignments: Use 12-point font, one-inch margins, and double-spaced pages in a plain font (such as Times New Roman or Calibri). Full

bibliographic information is only required for external resources (i.e., those not provided by the faculty/instructor).

Note for submissions: Please submit directly to Canvas and not through email.

Grade translation:

90-100%	A
80-89%	B
70-79%	C
60-69%	D
<59%	F

Participation	Students should demonstrate their engagement with the class materials, which may be through discussion in class, discussion during office hours, or through posts on the class discussion board.	50 points
Analytic Narrative Map	In Unit I, students will explore a range of first-person narratives of disabled people, and each of these class sessions will include a “narrative map” completed through small groups. The Analytic Narrative Map is an <u>individual</u> assignment and should compare/contrast narrative maps from at least <u>4 narratives</u> in one unified document.	25 points
Reflection Papers	There are 3 reflection papers. For each, students will write a 2-3 page response to the prompt related to the class materials and in-class discussion.	150 points (50 each)

Case Analyses	There are 2 case analyses. For each, students will need to follow the given template to unpack the case provided. Students should aim for 4-5 pages for each analysis.	150 points (75 each)
Final Project	There is a final project due during finals week, which may be a traditional paper (8-10 pages) or a creative project. The final project should clearly demonstrate the lens of disability bioethics. Creative options include creating a website, series of public-facing short essays (such as op-eds), designing a board game, for example. Students should contact the instructors with their idea for a final project before starting the project.	125 points
<i>For students not enrolled in graduate program</i>		= 500 points possible
GRADUATE STUDENTS ONLY: Triage Protocol Analysis	Graduate students will be asked to research triage protocols related to the COVID-19 pandemic (may be for a state, healthcare system, or individual institution). They will need to write 8-10 pages analyzing 1 protocol through the lens of disability bioethics. Not every feature of the triage protocol can be covered – focus on key features of the proposed plan.	+ 100 points
GRADUATE STUDENTS ONLY: Triage Protocol Presentation	Graduate students will be asked to give a presentation to the rest of the class based on the research they completed for the Triage Protocol Analysis. The presentation should use visual media (such as Power Point). Other presentation parameters (such as length) will be clarified and posted early in the semester.	+50 points

<i>ONLY for students enrolled in graduate program</i>	= 650 points possible
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COURSE POLICIES

- Email policy: Plan to check your email regularly; this will be the primary way in which you receive information outside of class.
 - Please be sure to email *both* Dr. Guidry-Grimes and Gargi for all course-related issues, unless it is a grading appeal or other sensitive matter that should only go to faculty.
 - **For all emails, please put “Disability Bioethics:” in the beginning of the subject line** to help ensure prompt response. Please be aware that emails are not routinely checked after hours (6 pm – 7 am).
- Office hours:

To schedule with Dr. Guidry-Grimes: Appointments for office hours will be in 20-min increments unless more time is needed. Please email faculty at least 24 hours in advance with the request for an appointment. Faculty will send the student a Teams link for these appointments at an agreed-on time, unless the student needs a different arrangement.

To schedule with Gargi: Please email me with a request to schedule office hours, including some days/times that work for you and information about your inquiry. This way, I can consult Dr. Guidry-Grimes prior to meeting if necessary to adequately answer your question(s).
- Class absence policy: Please contact the instructors once you have reason to believe you cannot attend a class session. If more than 3 classes are missed, the student will need to set up a meeting with faculty to discuss the student’s plan for success moving forward.

- Late submission policy: Students may request extensions, in advance, with justification. Late submissions without extension will receive a 5-point deduction for every 24 hours that it is late.
- Incompletes: Students may choose to receive an Incomplete if needed, in accordance with CWRU School of Medicine policies and procedures.
- In-person attendance policy: If a student has concerns about attending class sessions in-person, this should be communicated to the faculty as soon as possible. **If you have a confirmed or suspected contagious illness, please do not attend class in-person.**
- Professionalism and collegiality: The classroom is a place for respectful learning and engagement. The faculty will take every step possible to ensure a safe learning environment, and students are expected to be courteous and charitable to each other and to all instructors. A student may be asked to leave the classroom, at the discretion of the faculty, if the learning environment is being disrupted. If any student has concerns about psychological and intellectual safety, collegiality, or professionalism, please inform faculty or the department chair.
- Grade changes: Students have the right to appeal their grade. The student should make the request in writing with justification, sent directly to the professor for the course. Faculty will then set up a 30-minute appointment to discuss. Any grade changes are at the discretion of faculty.
- Cell phone use: Students are expected to turn off their cell phones during class. If there are extenuating circumstances (such as needing to be in touch with childcare), please let the faculty/instructor know at the beginning of class.
- Class intellectual property: Students are expected to abide by copyright laws with all class materials. If any student wants to distribute class lectures/handouts, please first contact faculty/instructor for permission. All class materials, including lectures, should be cited appropriately.

RESOURCES AVAILABLE

The Writing Resource Center is available for help with writing assignments, from beginning to end. For more information, or to make an appointment, visit <http://writingcenter.case.edu/>.

The Health Sciences Library has many resources available that you may find useful for this course. Library staff is also available to help with literature searches. For more information, please visit <http://case.edu/chsl/library/>.

DIVERSITY AND INCLUSION

It is the intent that all students regardless of their background and perspective be well-served by this class. Further, we intend to present material whose content is respectful of diversity (gender identity, sexuality, disability, age, socioeconomic status, ethnicity, race, nationality, religion, and culture) and deliver it in a way that respects these differences as well. We expect that all students, instructors and guests will help foster an atmosphere of respect, trust and safety in the classroom.

If you have suggestions for how to make the class content or environment more inclusive, or have specific incidents to report, please reach out to the instructor. If you are not comfortable reaching out to the instructor, feel free to reach out to someone else, such as the School of Medicine Graduate Education Office (som-geo@case.edu) or the Office of Inclusion, Diversity and Equal Opportunity (OIDEO) (oideo@case.edu).

More information on University policy and resources are available on [OIDEO's website](#).

Disability Accommodations

If any student would benefit from increased access or accommodations to enhance their learning experience, please do not hesitate to ask the faculty directly. I may be able to adjust the method/delivery of material, and I will advocate for you and help you navigate the process described below if requested.

In accordance with federal law, if you have a documented disability, you may be eligible to request accommodations from Disability Resources. In order to be

considered for accommodations you must first register with the Disability Resources office. Please contact their office to register at 216.368.5230 or get more information on how to begin the process. Please keep in mind that accommodations are not retroactive.

Academic Integrity

Any violation of the University's Code of Ethics will not be tolerated. All forms of academic dishonesty including cheating, plagiarism, misrepresentation, and obstruction are violations of academic integrity standards and will result in a minimum penalty of receiving a zero for the assignment, the potential for failing the entire course. Cheating includes copying from another's work, falsifying problem solutions or laboratory reports, or using unauthorized sources, notes or computer programs. Plagiarism includes the presentation, without proper attribution, of another's words or ideas from printed or electronic sources. It is also plagiarism to submit, without the instructor's consent, an assignment in one class previously submitted in another. Misrepresentation includes forgery of official academic documents, the presentation of altered or falsified documents or testimony to a university office or official, taking an exam for another student, or lying about personal circumstances to postpone tests or assignments. Obstruction occurs when a student engages in unreasonable conduct that interferes with another's ability to conduct scholarly activity. Destroying a student's computer file, stealing a student's notebook, and stealing a book on reserve in the library are examples of obstruction.

In addition, the incident will be reported to the Dean of Undergraduate Studies and Academic Review Board for undergraduates or Senior Associate Dean of Graduate Studies, for Graduate Students. The CWRU Statement of Ethics for graduate students can be found here: <http://case.edu/gradstudies/about-the-school/policies-procedures/>