Master of Arts in Medical Humanities, Compassionate Care & Bioethics

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Office Location: Center for Medical Humanities  
Health Sciences Center Level 3, Room 080

Office Hours:  
before each class

Meeting Dates: Wednesday evenings

Class Time: 6:00 to 8:30pm

Website: blackboard.stonybrook.edu

This course, an HCB elective, considers major debates in bioethics in light of recent scholarship in disability studies, drawing on perspectives from philosophy, history, and sociology. ‘Disability’ (and fear of future disability) has been central to bioethical debates since the field’s founding. Questions about human rights at the beginning and at the end of life, and the allocation of scarce resources such as organs to the sick, have turned on evaluations of ability and disability: what disability would lead to what form of suffering or quality of life. Bioethics draws on such evaluations to justify preventing the birth of an affected child, ending a life rather than enduring it, or passing over the affected person because someone else would obtain greater ‘benefit’ from an organ transplant or procedure such as dialysis.

While bioethics makes frequent use of ‘disability’ in philosophical inquiry and debate, only recently have the voices of people with disabilities and their family members, and the perspectives of disability rights, appeared in its journals and university curricula. People with disabilities challenge judgments about quality of life with physical impairments, and contribute to our understanding to issues of access to treatments and supports. They serve as a reminder that whether through age or illness, all of us are destined to join their ranks

Topical Overview
Module 1: Models of Disability  
Module 2: The Challenge of Cognitive Disability  
Module 3: Disability and “Perfect Babies”

Plan Ahead
1. Order or purchase copies of the course texts as soon as possible
2. Be thinking of a paper topic: first half of class on October 1 will be devoted to presentations by each student on a topic they might pursue for their final paper
Course Objectives

1. Student will be able to explain in detail how the biomedical practices of analyzing bodily differences contribute to collective understanding of individuals with disabilities as well as various disability communities.

2. Student, through exploration of the long history of eugenic thought and practice, as well as the identification of alternative traditions of mutual regard, will gain an appreciation for disabled people and their allies as potential agents of change.

3. Student will be able to explain and contest the marginal position of individuals with cognitive disability in discussions of moral responsibility and citizenship.

Schedule of Evaluation

This course will be run as a graduate seminar, with formal presentation of background material by course instructors, but the core of each class will be discussion of the readings and the cases for the week, with each week designed to explore a different set of ethical, social, and policy issues. Students are expected to read the assigned articles, chapters, and excerpts come to class prepared to discuss them.

Students will be asked to write a term paper on a topic in disability and bioethics. Proposed topics must be received by the instructor by the end of the third term of class (Friday, September 19) and finalized by the end of September. Students will have the opportunity to receive feedback on an outline or draft of the paper submitted up to 2 weeks before the official end of term.

Students will be expected to adhere to standard academic conventions for quotation and citation of sources. Any standard reference system, such as the University of Chicago, MLA, AMA or other system of citation is acceptable as long as it allows your readers to trace the origins of your claims to the original publication or source.

Reading responses are also required at the end of the first and third module.

Rough evaluation breakdown:

<table>
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<tr>
<th>Assessment</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Paper Proposal</td>
<td>%10</td>
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<tr>
<td>Module [1] Response</td>
<td>20</td>
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<tr>
<td>Module 2/3 Response</td>
<td>20</td>
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<tr>
<td>Final Paper</td>
<td>30</td>
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<tr>
<td>CP Class Participation</td>
<td>20</td>
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Note: CP score based upon assessment of student’s engagement w/ class readings/conversations.

In the first two weeks of class we will discuss the possible use of electronic discussion boards as an additional mode of communication between class sessions.

Feedback

Student papers will receive written comments, and we will assess group dynamics and participation regularly. In addition, the standard course evaluation form includes a faculty feedback section.
Readings
Three required texts for the course are available for purchase at the Health Sciences Center Bookstore on Level 2. They are also available from online bookstores and a variety of used book resellers. Additional readings will be distributed in .pdf format via the course blackboard site. Please advise the instructor if you have any difficulty accessing or using course readings.

REQUIRED


RECOMMENDED


**Calendar of Modules, Topics & Readings**

**Module 1: Philosophical and Historical Approaches to Disability**

This class is rooted in the fields of bioethics and disability studies. Grasping the contemporary disability experience requires a robust understanding of population patterns and dynamics. After an introduction to various definitions and models of disability, we will consider the histories of eugenic segregation and sterilization – an important context for the emergence of oppositional political bodies of disabled people. These perspectives have often been formed in opposition to the dominant worldview of professional fields such as medicine, rehabilitation and psychology. Key philosophical approaches challenge for us to conceive of disability differently, and you will have an opportunity to consider one or more discipline’s approach to disability for your written responses.

1.1 *Wednesday, August 27* - Introduction to the course

- Hunter College Disability Studies Project, “Definition of Disability Studies”
1.2 Wednesday, September 10 - The Exclusionary Response to Atypicality
First Half of Class
- DePoy & Gilson, *Rethinking Disability*, Chap 1: Foundations; Chap 2: Looking Back
Primary Source Documents on Redefining Disability
- Two Cripples, “The Sluggard and the Ant” (1918)
- From the Rehabilitation Act of 1973 (United States)

1.3 Wednesday, September 17 - Origins of the Exclusionary Response
First Half of Class
- DePoy & Gilson, *Rethinking Disability*, Chap 3: Disability in the 20th and 21st Centuries
Primary Source Documents on Disability Pride and Activism
- Jim Ferris, “Poems with Disabilities” (2000)
- *Parade* by Nussbaum (2000)
Second Half of Class
- DePoy & Gilson, *Rethinking Disability*, Section 2: Explanatory Legitimacy Theory

1.4 Wednesday, September 24 - Fashioning Communities
First Half of Class
- DePoy & Gilson, *Rethinking Disability*, Section 3: Fashioning Communities
- Union of the Physically Impaired Against Segregation, from *Aims* (1974)
Second Half of Class
- Goodley, *Disability Studies*, Chap 5: De-psychologizing Disability Studies

1.5 Wednesday, October 1 Sharing thoughts with peers and receiving feedback on Assignment 1
First Half of Class
- Student presentations from notes or drafts.
Second Half of Class – New Directions in Disability Studies

**Assignment 1: Your response to disability: through, across, and beyond disciplines**

Over the course of the first module we have considered broad patterns in society’s response to disability, and a variety of ways that professionals construct valid knowledge about atypical bodies. For the first 4-5 page response paper, consider one or two disciplinary approaches to physical difference – these can be inter-discipline or intra-discipline. How is disability constructed in this(these) account(s)? Where is the disability found? How is it dealt with? Are these constructions contested? If so, how?
For the assignment, atypicality may be considered broadly or narrowly.

Evaluation will consider the following:
- clear identification of discipline(s) and approaches
- reference to course readings and additional resources
- appropriate level of detail, including definitions

Module 2: The Challenge of Cognitive Disability to Individualization

In light of Goodley’s discussion (1.4 & 1.5) of psychology, individualization, and critical approaches to disability studies, we will devote several days to considering the social, cultural and environmental entanglements of people with a variety of cognitive differences that are captured in the term neurodiversity. Observations from the social sciences and the humanities shine a light on the moral lives of those too often written off as insufficiently ‘rational.’

Materials

Baker, Dana Lee, *The Politics of Neurodiversity: Why Public Policy Matters*. Boulder: Lynne Rienner Publishers, 2011. (Chapters available for download through Blackboard, however you may wish to purchase your own copy at the HSC campus bookstore or online.)

2.1 Wednesday, October 8 – Competing Disability Agendas in Public Policy
- An Anonymous Newtown Autistic, “My phobia and psychiatry survival story, neurodiversity and recovery, agency and access.” That Autistic That Newtown Forgot: Radical Thoughts Against Ableism, link

2.2 Wednesday, October 15 – Citizenship and Neurodiversity


2.3 *Wednesday, October 22 - Autism in Legislative and Popular Discourses*


2.4 *Wednesday, October 29 – Autism the Musical*


Module 3: Disability in the Age of Perfect Babies

With eugenic sterilization outlawed in the United States, women’s bodies and reproductive capacities became even more prominent in the years that followed. This section we will consider the emergence of the women’s movement and the disability rights movement as a response to, and impetus for, the enhanced role of medical professionals.

Materials


3.1 Wednesday, November 4 - German measles and the politics of abortion


3.2 Wednesday, November 11 – Choice, control and mother-blame

Landsman, Reconstructing Motherhood, Chaps 1, 2 & 3, pp 1 - 89.

3.3 Wednesday, November 17 - Disability and motherhood

Landsman, Reconstructing Motherhood, Chaps 1 thru 5, pp 1 - 170.


3.4 Wednesday, December 3 – Class Wrapup

First Half of Class
Debrief on the contemporary bioethics and pragmatics of genetic counseling.

Second Half of Class
Discussion of Assignment 2 and the final paper.

Assignment 2: The importance of stories: identities in formation and in opposition

(Due Friday, December 5)

In the second and third modules, we have considered the ways that meanings have attached themselves to particular medical diagnoses and conditions, at a variety of points along the lifespan. For the second 4-5 page response paper, offer a creative account of one body, family or community of difference. The resources for this account may be drawn from readings, personal experience or outside research. You may adopt either an ethnographic or fictional approach to the account but remember to include enough detail so that others may evaluate its truthfulness/persuasiveness.

Evaluation will look for the following:
- an account of how the difference was identified, described, made real
- creative description of the setting
- documentation appropriate to the selected genre

Final paper due 12:00 noon Wednesday, December 10
RUBRIC for evaluating response papers

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<tr>
<th></th>
<th>5 points full credit</th>
<th>4 points</th>
<th>3 points</th>
<th>2 point</th>
<th>1 point</th>
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<tbody>
<tr>
<td><strong>Creativity &amp; Coherence</strong></td>
<td>Well-structured; written with panache; uses concepts discussed in class</td>
<td>Competent but not clearly written; fails to grab the reader’s attention</td>
<td>Difficult to follow and understand</td>
<td>Does not follow the assignment.</td>
<td>[not used]</td>
<td>XX / 05</td>
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<tr>
<td><strong>English grammar and sentence mechanics</strong></td>
<td>Well written with very few proofreading or editorial marks</td>
<td>Some areas to improve indicated</td>
<td>Grammar &amp; structure errors; readability compromised</td>
<td>Not graduate level writing</td>
<td>[not used]</td>
<td>XX / 05</td>
</tr>
<tr>
<td><strong>Historical &amp; Sociological Insight</strong></td>
<td>Demonstrates command of appropriate historical and sociological contexts</td>
<td>Does not make demonstrate familiarity with key references</td>
<td>Largely disconnected with relevant precedents or examples</td>
<td>Does not respond to assignment</td>
<td>[not used]</td>
<td>XX / 05</td>
</tr>
<tr>
<td><strong>Bibliography and Use of Sources</strong></td>
<td>in-text citation of sources in text as well as a complete bibliography</td>
<td>References missing</td>
<td>References not clearly cited</td>
<td>Extremely faulty documentation of sources</td>
<td>No bibliography or citation of sources</td>
<td>XX / 05</td>
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**TOTAL** | XX / 20 |