

York University
Faculty of Health
School of Health Policy and Management

HLTH 5040

HEALTH, LAW AND ETHICS

FALL 2021

Seminar times/Location

Schedule: **Tuesday, 4-7 pm** (Online-Synchronous- Lien Zoom on eClass)

Term: Fall 2021 Term (September to December 2021)

Professor: Dr. Agnès Berthelot-Raffard

Office: Virtual (on Zoom-Synchronous)

Hours: After the class & by appointment

Email: aberthel@yorku.ca

COURSE DESCRIPTION

This seminar explores the interconnection between health and (bio-)ethics. Indeed, this seminar combines ethics, bioethics and public health ethics to examine issues at a broader social level and an individual level.

During Fall 2021, this seminar will focus on **disability ethics**. Relationship between health, ethics and disability rights will be explored, such as abortion, prenatal testing, growth-attenuation therapy, disability in the clinical setting.

This seminar uses critical disability studies and philosophy to enhance graduate students' capacity to understand and discuss public health issues and to strengthen their critical thinking about biomedical and clinical topics.

Please note that this course is led by **ethical perspective**. Consequently, it is not a formal health policy and equity course. Moreover, despite the presence of the term "law" in the seminar title, we will not address law issues as such.

METHODS OF TEACHING

The course is a seminar. Except for the introductory seminar, the instructor only lectures minimally. All other classes will consist of approximately 20-minute students' presentations. Students are responsible for introducing both synthesis and analysis by extracting central themes and identifying key questions raised by the texts. Following these presentations, our time will be devoted to a structured discussion of themes raised by the readings. This teaching method means that the success of this seminar will depend upon student preparedness and willingness to participate.

COVID UPDATES

With the resumption of most campus activities, and an evolving public health landscape, it is important for us to stay connected. The most up-to-date information about how COVID is affecting campus activities, including announcements and changes to university-wide protocols, is available on York's "[Better Together](#)" website. **The University has mandated vaccinations for anyone on campus**.

Most of the program's courses are scheduled for in-person delivery, with some courses designated for remote delivery. The expectation is that in-person courses and will be subject to York's policies regarding access to campus.

Before coming to campus each day:

- **Complete the COVID-19 screening (YU Screen) daily**
- The **course e-class site** (you need Passport York to sign in) is your information source for up-to-date course announcements. We encourage you to visit your course website **each morning before making your way to campus**.
- If we find ourselves in a situation where we need to shift modes -- for this course only (in-person / online etc.), or for a single class -- there will be an e-class announcement.
- Your course director will post course materials to the e-class site.
- Seminar courses, designed as in-person, will NOT be recorded nor posted to e-class. The classroom technology does not enable it and the format of a seminar course is not conducive to recording because it is reliant on participation, discussion and in-class exploration. We encourage students to share class notes in instances where peers cannot attend class, particularly given the myriad challenges of COVID.

Before coming to York Keele campus:

- Complete COVID-19 screening before coming to campus
- Visit your course e-class sites (you need Passport York to sign in) for up-to-date course announcements
- wearing a mask & maintaining social distance supports safety for all. for additional information [visit here](#)
- COVID-19 testing locations are available

Where to look for support and help:

The pandemic can impact students in different ways and CDS is committed to and focused on providing students with a learning environment that is engaging, supportive, flexible and has academic integrity. We encourage you to connect as early as possible about your learning experience so that we can have a deeper understanding of anything you may be facing and work together towards finding possible solutions.

- If you require some advice about **course related matters**, speak to your Course Director, Dr. Agnes Berthelot-Raffard, aberthel@yorku.ca

- If you require **administrative help and program-related forms**, speak with Collette Murray (gradcds@yorku.ca)
- For **academic advice** about the program, or your progress speak with your supervisors / advisors or the Graduate Program Director, Tamara Daly (gpdhlth@yorku.ca)
- A list of [important dates](#) at York:
- Information about access to [Wellness Consultation and Counselling Services](#), wellness resources, webinars and workshops for graduate students
- **Library Resources**
- [Academic Accommodations](#) through Student Accessibility Services
- [Centre for Human Rights, Equity and Inclusion](#)
- [Religious Observance](#)

ACADEMIC HONESTY

The [Faculty of Graduate Studies Academic Integrity Module](#) is designed to provide the graduate community with information and resources on the expectations of academic integrity at York University. Community members have an obligation to maintain the highest standards of academic honesty throughout their studies in accordance with the Senate Policy on Academic Honesty. Upon completion of this module, students will have a better understanding of what constitutes a scholastic offence, as well as their responsibilities in relation to a variety of academic principles.

EVALUATION METHODS

The evaluation will be based on the following components:

1) Oral presentation on a text (or a selection of texts) (40%)

An **oral presentation** to be chosen from the themes indicated below. Students must indicate their choice of selected texts in the first seminar. To facilitate an informed choice, students will be provided with elements of each theme at the first meeting. This evaluation method is based on the student's active participation and ongoing work. It must be noted that each student may be expected to give more than one presentation during the course. Students are expected to choose an article from the list provided in the calendar below and give an oral presentation. This presentation, limited to **20 minutes**, will highlight issues emerging from the course readings. The oral presentation is intended to be both synthesis and analysis comprising an exposition of the ideas and theses defended by the authors. The student will ensure that questions arising from the readings are raised in order to facilitate class discussion.

- **Guidelines for the oral presentation:**

For each presented article:

- a. Which concepts are developed in the texts?
- b. What are the main ideas being discussed in each article?

- c. What are the key points and issues identified in the reading?
- d. What are the author's assumptions?
- e. What are the author's arguments and main thesis?
- f. What are the possible points of convergence, divergence between the articles?
- g. Does one (or more) of the texts presented refer to an article/concept already encountered in the course? If yes, which are the major differences between the authors?
- h. What is your own point of view on the article and its ideas/arguments/conceptualization? Do you find some counterarguments regarding the article?
- i. Provide up to 3 discussion questions for each text presented in order to open the discussion with the classroom.
- j. Please do not use video or other forms of media. It is a graduate seminar
- k. **5 days after the class, each student will submit to the professor his/her/their oral presentation by writing.**

PLEASE NOTE: Based on the number of students registered for the course, they may be expected to give more than one presentation. In this case, an average of the marks will be used to calculate the final grade.

2) Research essay (40 %):

Students have to write a research paper that provides analysis, interpretation, and an argument based on in-depth independence on a dedicated topic. Students are free to choose a subject matter regarding disability.

This assignment is in **two steps**: detailed outline + research paper.

First stage, a written paper will first take the form of a **detailed outline (10%)**. Students will be asked to define their own research question **on disability ethics** and provide a detailed outline. (see guidelines on eClass or given in the classroom). This paper is due **no later than October 7, 2021**.

Evaluation criteria for the detailed outline:

All detailed outline should:

- Present the subject matter in 1000 words. What is exactly the subject matter? Why this subject matter constitutes an ethical issue? What is the principal literature on that? What are the authors assumptions?
- Present a thesis statement: what is your position of your chosen subject?
- List the major points that support your thesis.
- List supporting ideas or arguments for each major point.
- List the counter-argument (what someone opposed to your argument could answer you?)
- Present the structure of your research paper.
- Present a detailed bibliography of academic writings. Do not use grey literature. (References, abstract –not the abstract written by the author but a short abstract of your reading-, key-concepts).

The **second stage** will consist of a **research paper (30%)** on one of the subjects discussed in class. (**12-page**. Assignments should be **double-spaced in 12 point Times New Roman** font and adhere to the **style guide of your choice** (e.g. APA, MLA, Chicago). Cite all relevant references from the course syllabus or other sources with page numbers). **By December 9, 2021 at the latest**, students must submit a **research paper** on their chosen subject.

Evaluation criteria for the research paper:

- Students must demonstrate in their writing a strong knowledge about the chosen topic: paper addresses the essential elements related to the topic, the ethical issues, the essential arguments raised by the authors in order to demonstrate an understanding of the different positions and problematics on this issue. Ideas are supported by examples if appropriate. Students should also use course concepts.
- Student should engage with a variety of sources and make an original contribution to the debate on disability ethics. Paper must integrate their own ideas/positions and how their ideas interact with those of the other authors.
- Student must present their ideas in a fluid manner. Paper should follow a logical flow of ideas; grammatically correct sentences and paragraph structure.

3) Class Participation (20 %):

Participation will be assessed based on students' attendance (5%) and participation in classroom discussion (5%). For this assessment, the Professor will pay attention to the quality of their participation and the general level of preparedness (10%) as revealed by participation. If needed, the instructor will reserve the right to call upon students during the seminar.

LANGUAGE OF EXPRESSION

Student presentations, and class participation are in English. Nevertheless, due to the *Canadian Charter of Rights and Freedoms*, students are free to complete all written assignments for this course in either English or French.

READINGS

All readings are available in PDF or e-book format at <http://www.library.yorku.ca> or are free at the URLs listed in the weekly schedule.

PLEASE NOTE : This text indicated below by **** is available on E-class. This text indicated ### can be found by inter-library loans:. Please make sure to order the sources, several weeks before the class.

WEEKLY SCHEDULE

CLASS 1: INTRODUCTION TO THE SEMINAR (September 14)

- Course Presentation
- Ethics, bioethics or public health ethics?

- Disability studies and Disability Ethics: some definitions.

PART 1: DISABILITY, PUBLIC HEALTH AND BIOETHICS

CLASS 2: DISABILITY: DEFINITION AND THEORIES (September 21)

- Barnes, Elisabeth (2020), Disability, Health, and Normal Function, in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press, 5-19.
- David Wasserman, Adrienne Asch, Jeffrey Blustein, and Daniel Putman (2016), Disability: Definitions, Models, Experience, *The Stanford Encyclopedia of Philosophy*,
- Susan Wendell, Susan (1996), *Rejected Bodies: Feminist Philosophical Reflexion on Disability*, New-York Routledge [chap 1: Who is Disabled? Defining Disability]

CLASS 3: DISABILITY RIGHTS AND BIOETHICS (September 28)

- Rosemarie Garland-Thompson (2017), Disability Bioethics: From Theory to Practice, *Kennedy Institute of Ethics Journal*, 27:2, June 2017, 323-339.
- Joseph A. Stramondo (2016), Why Bioethics Needs a Disability Moral Psychology, *Hasting Center Report*, May-June 2016, 22-30.
- Tom Shakespeare (2016), Just What Is the Disability Perspective on Disability? *Hasting Center Report*, May-June 2016, 31-32.
- Alicia Ouellette (2011). *Bioethics and Disability. Towards a Disability Conscious Bioethics*, Cambridge University Press [Chap: The Struggle: Disability Rights versus Bioethics]

CLASS 4: PUBLIC HEALTH ETHICS AND DISABILITY JUSTICE (October 5)

- Bonnielin K. Swenor (2021) Including disability in all health equity efforts: an urgent call to action, *The Lancet*, 6, June 2021, 359
- Editorial *The Lancet Public Health* (2021) Disability-a neglect issue in public health, volume 6, June 2021
- Bill Gaventa, Devan Stahl and Katherine McDonald (2020), Public Health Ethics and Disability: Centering Disability Justice in Donal J. Lollar et al. *Public Health Perspectives on Disability: Science, Social Justice, Ethics and Beyond*, Springer, 129-148.
- Daniel Golberg (2020), Epistemic Injustice, Disability Stigma and Public Health Law, in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press, 33-46.
- Anders Moller (2015), Disability from a public health perspective, *Scandinavia Journal of Public Health*, 43 (suppl 16), 81-84.
- Donal J. Lollar and John E. Crews (2003), Redefining the Role of Public Health in Disability, *Annual Revue of Public Health*, 24, 195-208.

OCTOBER 12: READING WEEK. NO CLASSES OR OFFICE HOURS.

PART 2: REPRODUCTIVE ISSUES

CLASS 5: EUGENICS & DISABLED REPRODUCTIVE RIGHTS (October 19)

- Ani. B. Satz (2020), Healthcare As Eugenics in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press, 20-32.
- Elizabeth Tilley, Jan Walmsley, Sarah Earle and Dorothy Atkinson (2012), “The Silence is roaring”: Sterilization, reproductive rights and women with intellectual disabilities, *Disability and Society*, 27:3, 413-426.
- Alicia Ouellette (2011). *Bioethics and Disability. Towards a Disability Conscious Bioethics*, Cambridge University Press [Chap 5: The Reproductive Years]

CLASS 6: ABORTION (October 23)

- Mary Anne Case (2020), Abortion, the Disability of Pregnancy and the Dignity of Risk in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press, 51-63.
- Ruth Hubbard (2006), Abortion and Disability. Who Should and Who Should Not Inhabit the Word?, in. L. Davis, *Disability Studies Reader*, Routledge, 93-103.
- Keith Sharp & Sarah Earle (2002), Feminism, Abortion and Disability: Irreconcilable differences? *Disability & Society*, 17(2), 137-145.
- Judith Jarvis Thomson (1971), A Defense of Abortion, *Philosophy and Public Affairs*, 1:1 (autumn 1971), 47-66.

CLASS 7: PRENATAL TESTING (November 2)

- Amber Knight and Josuah Miller (2021), Prenatal Genetic Screening, Epistemic Justice and Reproductive autonomy, *Hypathia*, 36, 1-21.
- Marie-Eve Lemoine and Vardit Ravitsky (2020), The Down Syndrome Information Act and “Mere difference”: Redefining the Scope of Prenatal Testing Conversations? in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press, 64-76.
- Adrien Ash (1999), Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy, *American Journal of Public Health*, Nov 1999, 89:11,1649-1657.

PART 3: DISABILITY IN THE CLINICAL SETTING**CLASS 8: PEOPLE WITH DISABILITY IN MEDICAL PRACTICE (November 9)**

- Adam Cureton (2020), Expressing Respect for People with Disabilities in Medical Practice in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press, 93-103.
- Omar sultan Haque and Michael Ashley Stein (2020), Humanizing Clinical Care for Patients with Disability, in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press, 117-128.
- David M Pena-Guzman, Joel Michael Reynolds (2019), The Harm of Ableism: Medical error and Epistemic Injustice, *Kennedy Institute of Ethics Journal*, 29: 3, september 2019, 205-242.

CLASS 9: AGEING (November 16)

- Monique Lanoix, Aging and the Prudential Lifespan Account, *Medecine, Health Care and Philosophy*, 24: 3,351-366
- Rebecca Dresser (2020), Dementia, Disability and Advance Medical Directives: Defenseable Standards for Dementia Care, in I.Glenn Cohen, C. Shachar, A. Silvers et al. *Disability, Health, Law and Bioethics*, Cambridge University Press,77-88.
- Monique Lanoix (2007), Dementia as Moral Harm, *American Journal of Bioethics*, 7:6, 59-60.
- ****Susan Sherwin (1998), A Relational Approach to Autonomy in Health Care, in F. Baylis, B. Hoffmaster, S. Sherwin and K. Borgerson (2012), *Health Care Ethics in Canada*, Toronto, Nelson Education, 242-258.

PART 4- SELECTED CASE STUDY: THE ASHLEY'S TREATMENT

CLASS 10: GROWTH-ATTENUATION THERAPY (November 23)

- Steven D. Edwards (2011). The Case of Ashley X, *Clinical Ethics*, 6, 39-44.
- Adrienne Asch, Anna Stubblefield (2010), Growth Attenuation: Good Intentions, Bad Decision, *The American Journal of Bioethics*, 10 (1), 2020, 46-48.
- Dick Sobsey (2009), Cutting Edge Treatment-pain and Surgery in the Ashley X Case, *Development Disabilities Bulletin*, 2009, 37(1), 63-90.
- Tom Shakespeare (2007), Not convenience, but dignity: the stature of disabled person. *Clinical Ethics*, 3, 2-3.
- Daniel F. Gunther, Douglas S. Dickema (2006), Attenuating Growth in Children With Profound Developmental Disability, *Archives of Pediatrics and Adolescence Medicine*, 60 (Oct 2006), 1013-1017.

CLASS 11: CAREGIVING OF DISABLED MINDS (November 30)

- ##### Lisa Freitag, Joan Liaschenko (2017), Holding Ashley (X): Bestowing Identity Through Caregiving in Profound Intellectual Disability, *Journal of Clinical Ethics*. 2017 28:3 (Fall 2017); 189-196.
- Eva F. Kittay (2019), *Learning from my Daughter: The Value and Care of Disabled Minds*, Oxford University Press, [Chapter 9: Forever Small. The Strange Case of Ashley X
- Alicia R. Ouellette (2008), Growth Attenuation, Parental Choice, and the Rights of Disabled Children: Lessons from the Ashley X Case, *Houston Journal of Health & Policy*, 8, 207-244.
- Mathiew Liao, Julian Savulescu and Mark Sheenan (2007), The Ashley Treatment: Best interests, Convenience and Parental Decision-Making, *The Hasting Center Report*, 37(2), 16-20.

Complementary readings:

- Meryl Eschen Mills (2013), The Legal and Moral Implications of Growth Attenuation, *Health Law and Policy Brief*, 1(2), 12-23.
- Jilian Komblatt (2009), The Ashley Treatment: The Current Legal Framework Protects the Wrong Rights, *Minnesota Journal of Law, Science & Technology*, 10 (2), 773-800.

-Benjamin S. Wilfond (2007), Policy & Politics: The Ashley Case: The Public Response and Policy Implications, *The Hasting Center Report*, 37(5), 12-13.

GRADING SCALE

Assignments will bear either a letter grade designation or a corresponding number grade (e.g. A+ = 90 to 100, A = 85 to 90, A- = 80-84, B+ = 75 to 79, etc.)
(For a full description of grading at the graduate-level, please visit [here](#))

COURSE POLICIES

1. Assignments should be **double-spaced in 12 point Times New Roman** font and adhere to the style guide of your choice (e.g. APA, MLA, Chicago).
2. Cite all relevant references from the course syllabus with page numbers.
3. **Submit assignments via Turnitin** by midnight on the due date.

PLEASE NOTE:

If you have a medical or other compelling reason for not submitting an assignment on time, I **must be notified PRIOR to the date the assignment is due**. If this is not done, then the **2 percentage points a day** penalty applies without exceptions.

The professor will not accept assignments weeks late without prior notification. If there is a need for academic accommodation, arrangements are made in advance with the York Student Accessibility Services. If there are any additional supports required on a personal level, please feel free to contact Graduate Wellness Services.

Late Penalty: **The assignments received later than the due date will be penalized 2% for every day late** (including weekends). Exceptions to the lateness penalty for valid reasons such as illness, compassionate grounds, etc., may be entertained by the course instructor but will require supporting documentation (e.g., a doctor's or allied health professional's letter).

For guidelines around grading practices, missed assignments and late work, see the Student Survival Guide & Handbook at https://cds.gradstudies.yorku.ca/files/2020/10/CDIS-Handbook-2020-2021_FINAL.pdf?x49507 (Turn to pages 19-20, 27, and 33 for policies on our Grading System, Course Extensions, Academic Honesty, and Academic Accommodation for Students with Disabilities.)

NOTE ON LEARNING ENVIRONMENT

Expression of racism, sexism, ableism, homophobia or transphobia would not be tolerated in the classroom. Your instructor will foster a supportive, inclusive learning environment that will encourage both individual and collective growth. However, inclusivity is a social responsibility. That means that students are also responsible to do their best to create an anti-oppressive and collegial environment. Implicit forms of oppression such as whitewashing, or mansplaining will be not tolerated.