January 2019 (1-11-2019)

HCB 511  Bioethics, Disability & Community
Room 067

Meeting Dates:
Week One
Jan. 8 (Tuesday) Alex Wagner, SG Post
Jan. 9 (Wednesday) Robyn McKeefrey
Jan. 10 (Thursday) Robyn McKeefrey

Week Two
January 15 (Tuesday) Linda Bily
January 16 (Wednesday) Alex Wagner
January 17 (Thursday) Linda Bily

Week Three
January 22 (Tuesday) Alex Wagner
January 23 (Wednesday) SG Post
January 24 (Thursday) SG Post

Class Time: 5:15 to 9:00pm

Co-instructors:

Stephen G Post, PhD (instructor or record)
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**Background**

The acrimonious conflict between the bioethics and disability movements is well recognized. Disability advocates have long been critical of the eliminatory mindset of prenatal testing and selective abortion. But there are many other areas of significance where bioethics runs against the grain of disability advocates and affected individuals, including exclusionary hypercognitive theories of “personhood” and moral status,” diminished reproductive rights, resistance to life-extending medical interventions, narrow and dismissive perspectives on quality of life and well-being, the affirmation of non-disabled values such as independence and autonomy, utilitarian theories of justice and rationing according to “social worth,” and a general medical model of disability as dysfunction. Questions about human rights at the beginning and at the end of life, and about the allocation of scarce resources such as organs to the sick, have turned on evaluations of ability and disability.

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 and cognitive impairments, and contribute to our understanding to issues of access to treatments and supports.

**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 disabilities in discussions of moral responsibility and citizenship.

**Readings**

There is one major text for this course that you should order immediately and read in its entirety by January 8. This is Alicia Ouellette’s *Bioethics and Disability: Toward a Disability-Conscious Bioethics* (Cambridge University Press, 2013). This is an excellent book for our course because it covers the disagreements between disability advocates and bioethicists with great clarity. It also proceeds nicely by section on the general topics of

- Infancy
- Childhood (including Ashley X)
- The Reproductive Years
- The Adult Years
- The End of Life

The book wraps up with a great section “Toward a Disability-Conscious Bioethics.”

By reading this book now you will have a lot of strong background in place before we actually start the course.

**Assignment One:** On January 8 come to class with a thoughtful 5-page double-spaced reflection on the tensions between disability advocates and bioethicists, and some possible resolutions, as put forward by Alicia Ouellette in her book.

**Course Calendar and Topics**

**Week One**

*January 8, 6pm (Tuesday) Introduction to the Course and Models of Disabilities*

Faculty: Alex Wagner, SG Post

We will explore models of disability as tools for defining impairment and, ultimately, for providing a basis upon which government and society can devise strategies for meeting the needs of disabled people.

We will also clarify the historic tensions between disability advocates and the bioethics movement. Go to [www.NotDeadYet.org](http://www.NotDeadYet.org) and examine their strong ethical stances against assisted suicide, euthanasia, futility, and various others issues that come up in bioethics debates. Read with care and prepare for discussion.

We will begin with a discussion of Ouellette, pages 1 – 71 (page 67 does a nice job of summarizing various tensions), and then turn to the reading listed below:

**Readings**


*Bioethics and Disability* text, chapters 1 & 2
**January 9, 5:30 pm (Wednesday) The Eugenics Movement and Modern Day Eugenics: Designer Babies**  
Faculty: Robyn McKeefrey

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 us to conceive of disability differently and consider different approaches against and for the conception of designer babies.

**Readings**

*Bioethics and Disability* text, chapter 3.

**January 10, 5:30 pm (Thursday) Sexuality and Reproductive Justice for Women with Disabilities**  
Faculty: Robyn McKeefrey

Women with intellectual and developmental disabilities have long been violated by the instruments of eugenics such as: physical and communication barriers to obstetrical and gynecological services; forced abortion, overuse of long-acting contraceptives; and the loss of child custody. We will explore these and other instruments which continue as barriers to sexual health and reproductive justice.

**Readings**


Silvers, A., Francis, L. P., & Badesch, B. (2016). Reproductive rights and access to reproductive services for women with disabilities.


*Bioethics and Disability* text, chapter 5.

**Assignment Two:** Come to class on January 15 with a thoughtful 5-page double-spaced reflection on some of the key issues covered in Week One.

**Week Two**

*January 15, 5:30 pm (Tuesday) Introduction to the ADA: From Theory to Reality*

Faculty: Linda Bily

Students will explore the five unique areas addressed by the Americans with Disabilities Act and Amendments, the organizations responsible for enforcement and the practical aspects of this legislation. An interactive field study will define your perception of the ADA and address the issues in real time.

**Readings**

Required

[www.ADAbasics.org](http://www.ADAbasics.org)

This online course covers ADA basics and provides CEU credit. Please complete before our first session.


**January 16, 6 pm (Wednesday) Disabilities and the Role of Ethics and the Impact of Bias**  
Faculty: Alex Wagner  

Are you aware of your personal prejudices, inherent, learned and societal? Is your understanding of disabilities accurate?  

**Readings**

**Required**  
McDonald, Anne. "Crossley, Rosemary and McDonald, Anne.  
Nancy Mairs, "Plunging In."  
Robert F. Murphy, “The Damaged Self.”

**January 17, 5:30 pm (Thursday) Who Will Care for the Children?**  
Faculty: Linda Bily  

There is a slippery slope when addressing the physical, emotional and psychosocial needs of children with a disability. Who defines the needs, or rights, of the child and parents? What happens when gender dysphoria is a contributing factor?  

**Readings**

**Required**  
Lawsuit: ADA’s “gender dysphoria” exclusion is discriminatory  
http://www.rootedinrights.org/lawsuit-adas-gender-dysphoria-exclusion-is-discriminatory/  

Puberty-Blocking Hormone Therapy for Adolescents with Gender Identity Disorder: A Descriptive Clinical Study

*Bioethics and Disability* text, chapter 4

Recommended

Access to HC for Transgendered Persons: Results of a Needs Assessment in Boston
http://www.tandfonline.com/doi/abs/10.1300/J485v08n02_08


Providing Cross-Gender Hormonal Therapy for Transgender Patients

**Assignment Three:** Come to class on January 22 with a thoughtful 5-page double-spaced reflection on the some of the key issues covered in Week Two.

**Week Three**

**January 22, 6 pm (Tuesday) a) Down Syndrome**
Faculty: Alex Wagner & Stephen Post

...We will focus on the positive option of true inclusion (mutuality, common humanity, inclusivity) in the context of L’Arche and the life work of Jean Vanier, Templeton Prize Winner. What is the nature of mutuality in this context? (SGP and JV have been friends for 25 years.)

*Videos Before Class*
https://www.youtube.com/watch?v=vDnfHQu-rg  L’Arche Intro

*Videos In Class*
https://www.youtube.com/watch?v=XWru3lZPzo  Templeton Prize

*Readings*

*Bioethics and Disability* text, chapter 6

**January 22, 6 pm (Tuesday) b) The Brooke Ellison Story**
We will watch *The Brooke Ellison Story* in class and talk about medical treatment and withdrawal in people with quadriplegia.
**January 23, 6 pm (Wednesday) Age-Related Cognitive Changes (ARCC)**
Faculty: Alex Wagner & Stephen Post

We will focus on the problem of “hypercognitive values” and bias against deeply forgetful people. We will focus on continuity of selfhood and its implications, and on many additional concerns and issues…

**Readings**


Read what you can from the website [www.musicandmemory.org](http://www.musicandmemory.org).


*Bioethics and Disability* text, chapter 7

**January 24, 6 pm (Thursday) The Bioethicists Gone Wrong?**
Faculty: Stephen Post

**Readings**

*Bioethics and Disability* text, chapters 7 & 8

**Assignment Four:** Hand in a thoughtful 5-page double-spaced reflection on the some of the key issues covered in Week Three by January 27.

**Grading**

Attendance and participation 20%

Module Assignments 20% x 4 = 80%

**From Official Stony Brook University Policy:**

*Statements required to appear in all syllabi on the Stony Brook campus:*
Americans with Disabilities Act:
If you have a physical, psychological, medical or learning disability that may impact your course work, please contact Disability Support Services, ECC (Educational Communications Center) Building, room128, (631) 632-6748. They will determine with you what accommodations, if any, are necessary and appropriate.

Academic Integrity:
Each student must pursue his or her academic goals honestly and be personally accountable for all submitted work. Representing another person's work as your own is always wrong. Faculty are required to report and suspected instances of academic dishonesty to the Academic Judiciary. Faculty in the Health Sciences Center (Schools of Health Technology & Management, Nursing, Social Welfare, Dental Medicine) and School of Medicine are required to follow their school-specific procedures. For more comprehensive information on academic integrity, including categories of academic dishonesty, please refer to the academic judiciary website at http://www.stonybrook.edu/uaa/academicjudiciary/

Critical Incident Management:
Stony Brook University expects students to respect the rights, privileges, and property of other people. Faculty are required to report to the Office of Judicial Affairs any disruptive behavior that interrupts their ability to teach, compromises the safety of the learning environment, or inhibits students' ability to learn. Faculty in the HSC Schools and School of Medicine are required to follow their school-specific procedures.