Summer One June 2017

HCB 511  Bioethics, Disability & Community
Room 067

Meeting Dates:
Week One (Michelle Ballan): June 5 (Monday), 7 (Wednesday), 8 (Thursday)
Week Two (Linda Bily): June 13 (Tuesday), 14 (Wednesday), 15 (Thursday)
Week Three (Stephen Post): June 20 (Tuesday), 21 (Wednesday), 22 (Thursday)

Class Time:  6:00 to 9:00pm

Co-instructors:
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Background

The deeply 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 (e.g., the famous cases of allowing newborns with Down syndrome and a correctable underlying esophageal blockage to die of dehydration/starvation resulting in the Baby Doe regulations), 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 are two brief required books for the class, as listed in Week Three. Readings for each class will be distributed in .pdf format. Those interested in recommended readings might consider:


**Course Calendar and Topics**

**Week One**

*June 5 (Monday) Introduction to the course and Models of Disabilities*

Faculty: Michelle Ballan, PhD

Grasping the contemporary disability experience requires a robust understanding of population patterns and dynamics. 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.

**Readings**

June 7th (Wednesday) The Eugenics Movement and Modern Day Eugenics: Designer Babies
Faculty: Michelle Ballan, PhD

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


June 8 (Thursday) Sexuality and Reproductive Justice for Women with Disabilities
Faculty: Michelle Ballan, PhD

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.


Module I Assignment

For Module 1, students will be required to complete an Op-Ed. You will create a seven to nine minute Op-Ed speech which you will record and submit as an assignment. Your speech will be on a disability topic area in which there have been problems, debate or media controversy. You will draw on the models of disability, bioethical principles, and other topics discussed in class this week, in an analysis of the disability topic. You will be evaluated on the strength of your content, argument, and delivery. You should draw upon research to substantiate your arguments. Students should include at least 1 visual aide in their presentation (e.g., a graph, diagram, video clip or picture) to illustrate a point or points. You must also email Dr. Ballan a reference list with your Op-Ed, however no other written work is submitted. You should cite articles and other scholarly works beyond class articles, not simply websites. The goal of this assignment is for you to evidence progress towards ability to apply critical thinking skills and applied bioethics concepts learned in class via readings, to a disability topic of relevance discussed this week. You will post your Op-Ed on YouTube.
**Week Two**

**June 13 (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.


**Recommended**


**June 14 (Wednesday) Disabilities and the Role of Ethics and the Impact of Bias**  
Faculty: Linda Bily

Are you aware of your personal prejudices, inherent, learned and societal? Is your understanding of disabilities accurate? A role-playing activity may shatter your beliefs about disabilities. Please bring a laptop or smart phone to this class session.

**Readings**

**Required**


**Recommended**


**June 15 (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  

**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

**Module II Assignment TBD**

The poster has become a staple of scientific communication at academic symposiums and scientific conferences. The data and data analyses are visually available in a well-developed poster presentation. Students will create a poster highlighting a disability issue with underlying ethical implications. Size, format and content are at the discretion of the student. It is hoped that these posters will translate to flyers that can be distributed during National Disabilities Awareness Month (October) to heighten the awareness of faculty, staff and visitors to the challenge of addressing disabilities in a medical humanities environment.

**Week Three**

**June 20 (Tuesday) Down Syndrome: Jean Vanier or Baby Doe?**
Faculty: Stephen Post

We will visit the new Long Island L’Arche Center in Riverhead and/or Maryhaven Center of Hope at St. Charles in Port Jefferson, and discuss the writings of L’Arche Founder and Templeton Prize Winner Jean Vanier.

*Readings*


**June 21 (Wednesday) Alzheimer Disease: Dan Cohen or T-4**
Faculty: Stephen Post

We will visit to Long Island Veterans Home Dementia Wing on the Stony Brook Campus.

*Readings*


**June 22 (Thursday) Eva Kittay**
Faculty: Stephen Post

A video visit to the Discovery Center with Eva Kittay.


Readings


Module III Assignment

Please write a five-page paper in response to the following question: What can people with cognitive disabilities teach us about (a) community, (b) respect for persons, and (c) the limits of mainstream bioethics.

Grading

Attendance and participation 25%
Module Assignments 25% x 3 = 75%

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.