Ethical Considerations When Working with Individuals with Disabilities: A Student's Perspective on Curriculum Design and Development

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Samantha Lauren Bowyer

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ABSTRACT

ETHICAL CONSIDERATIONS WHEN WORKING WITH INDIVIDUALS WITH DISABILITIES: A STUDENT'S PERSPECTIVE ON CURRICULUM DESIGN AND DEVELOPMENT

By Samantha Lauren Bowyer

Over the past several decades, disability rights have emerged as a growing concern within American society. A push for legislation to establish and uphold the rights of individuals with disabilities resulted in several landmark changes that affect the services and entitlements of those with disabilities. In addition, disability rights activists have worked to create a paradigm shift, in which disability is not thought of as a problem but rather as a difference. These societal-level changes have affected the ways in which medical professionals interact with patients with disabilities. Coupled with advancements in medical, reproductive, and assistive technology, changing perceptions about long term care and "death with dignity", and a more global society in which patients may come from varying backgrounds and belief systems, these changes will require that medical professionals be well-versed in ethical considerations specific to working with individuals with disabilities. It is important to not only examine ethics through the eyes of various healthcare professionals, but also to examine the ways in which scholars from other disciplines may approach the topic of healthcare ethics relating to disabilities.

This paper provides a first-hand account of the process of devising a university course on medical ethics to meet the growing needs of health care practitioners and others who will be working with individuals with disabilities. The first section of the paper discusses the necessity of such a course within an undergraduate curriculum. The second section discusses the author's personal experience in designing the ethics course curriculum, providing the reader with a rationale for specific structural components of the course design. The third section provides an analysis of the readings and pieces of media selected for course inclusion and how such media contributes to the students' experience in the course. The paper concludes with a reflection by the author on the process of curriculum design and development.

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by Samantha Lauren Bowyer

Approved by:

________________________________, Advisor
Dr. Laura Kelly

Kathleen Hutchin
________________________________, Reader
Dr. Kathleen Hutchinson

________________________________, Reader
Dr. Sean Duncan

Accepted by:

________________________________, Director
University Honors Program

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To Mom, Dad and Andy for their continual love and support.

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CHAPTER I

Introduction

One could reasonably state that individuals in all lines of work are expected to, and should, behave in an ethical manner. Not many would think twice before agreeing that it is unethical to steal money from a company, to falsify research results, or to provide standardized test answers to elementary school students. But what if the ethical dilemma at hand was more complicated? How would one respond to a client wanting to have a life-altering surgical procedure performed on their severely disabled child? Should a professional, at the request of a patient, provide medication to end the patient's life? Is it justifiable to provide prenatal genetic testing, which could give parents the opportunity to abort a child with disabilities? The answers to these questions are not as blatantly obvious. A variety of factors, both personal and societal, affect how a healthcare professional might view the appropriate course of action for a given ethical dilemma.

In American society, advancements in medical, reproductive, and assistive technology, changing perceptions about long term care and the right to "die with dignity", and a more global society in which patients may come from varying backgrounds and belief systems shape the ways in which healthcare professionals interact and provide care for patients. In recent years, a call for upholding the rights of individuals with disabilities has also altered the ways in which individuals with disabilities are provided services, both healthcare-related and otherwise. Legislation, such as the Americans with Disabilities Act, establishes a framework for both legal and perceptual shifts in how individuals with disabilities are treated and viewed (U.S. Department of Justice, 2005). Likewise, these changes have impacted the health field, necessitating a greater understanding of ethical considerations when working with individuals with disabilities.

A growing civil rights movement for individuals with disabilities has led to the establishment of disability studies programs or similar fields of study at universities across the United States. As a cross-disciplinary field, disability studies programs lend themselves well to coursework from different perspectives. Subjects ranging from English and the humanities, to healthcare-related fields, such as Speech Pathology and Audiology may be included in disability studies programs (Miami University Department of Sociology and Gerontology, n.d.). The examination of artistic and written work by individuals with disabilities can be studied similarly to works created by individuals associated with other minority cultures. Fields such as law and architecture require knowledge of public policy relating to disability rights. Education, healthcare, and business professions require interaction with individuals with disabilities. Professionals in any field can benefit from coursework dealing with ethical considerations associated with disabilities and healthcare. An interdisciplinary course focusing specifically on the subject would be an asset to students from any field of study.

This paper will examine the process of creating a course to fill the void in disability ethics education in undergraduate curricula. The first section discusses the need for ethics education with a specific focus on disabilities and healthcare. Specifically, this section will cover recent changes in legislation, health-related technologies, and population composition that affect the ways in which healthcare professionals interact with clients with disabilities. The second section covers the author's experience designing a course for potential inclusion in Miami University's Disability Studies minor through the Department of Speech Pathology and Audiology. This section provides rationale for specific structural components of the course's design, such as methods of evaluation and assignments embedded within coursework. The third section provides an overview of the readings and other forms of media included in the course content, with analysis of how such media will enhance students' experiences in the course. The paper concludes with a final reflection by the author on the process of curriculum design and development. Readers will gain a greater understanding of the necessity of ethics education in regard to disabilities and the process by which an undergraduate course may be designed to foster meaningful learning and understanding in regard to ethics within the constantly evolving field of disability studies.

CHAPTER II

A Growing Need for Disability Studies and Ethics Education

In the face of changing legislation regarding disability rights and healthcare, improving and growing health-related technologies, and a changing population composition in which clients may come from varying backgrounds, the importance of disability studies education is evident now more than ever. Such training specifically related to professional ethics should be deemed an integral part of undergraduate curricula for future professionals who will work with individuals with disabilities. However, individuals from any field of study can also benefit. "Contrary to popular perception of the term as a static set of principles or prohibitions, ethics is a continuous and dynamic decision-making process that ultimately seeks to render a judgment about human conduct" (Payne, 2011, p. 279). A variety of influences including religion, law, politics, economics, science, and culture affect the ethical decision-making process of an individual (Payne, 2011). Thus, one can see how, over time, what one deems as ethical may change. It is important to consider how culture directly affects the ethical decisions one makes and how the present climate in the United States necessitates a greater examination of professional ethics when working with individuals with disabilities.

Legislation

The latter half of the twentieth century saw the passage of much legislation with a focus on the rights of individuals with disabilities (U.S. Department of Justice, 2005). Growth in legislation may be attributed in part to the disability rights movement and the push for equality that characterized the 1980s and 1990s in the United States (The Smithsonian Institution, 2000). The Americans with Disabilities Act (ADA) is an example of such legislation. The ADA prohibits discrimination based on disability in employment practices, public accommodations, commercial facilities, transportation, and telecommunication (U.S. Department of Justice, 2005). The Civil Rights of Institutionalized Persons Act mandates that standards of care and living conditions be upheld for individuals living in nursing care facilities and homes or rehabilitative facilities for individuals with developmental disabilities or mental illnesses (U.S. Department of Justice, 2005). The Individuals with Disabilities Education Act (IDEA) mandates free and appropriate public education to children with disabilities (U.S. Department of Justice, 2005).

The aforementioned laws demonstrate the current value placed on disability rights in the United States. In the past, disability was seen as a medical condition that caused impairment or limitation. Disability was a problem that was dealt with at the individual level, rather than being a societal concern (Areheart, 2011). In recent years, the model of disability has shifted. Disability is now defined by the social constructs that restrict a group of individuals (Areheart, 2011). For example, an individual's inability to access a building due to a physical disability is no longer viewed as a problem caused by the individual's physical limitation, but rather a fault of society for designing a building that is inaccessible to the person. It is the responsibility of the society to provide buildings that are universally accessible. Legislation has been created to uphold the new definition of disability (U.S. Department of Justice, 2005). This paradigm shift and the creation of related legislation has been a landmark of the era, and would not exist without the work of individuals with disabilities and advocates pushing for change.

In addition to legislation created specifically to protect the rights of individuals with disabilities as a whole, legislation also exists that impacts specific groups of individuals with disabilities. Laws associated with end-of-life care provide an example of legislation that was created for the general public but can have significant consequences for individuals with disabilities. In 1976, a New Jersey Supreme Court ruling, commonly known as the Karen Ann

Quinlan case, upheld the right to refuse medical treatment (McGowan, 2011). That is, refusal can be made by a competent adult or by an individual who has been appointed as the decision-maker should the individual become unable to make the decision for himself (McGowan, 2011). The problem exists, however, in assessing one's mental capacity to make decisions for oneself. Legal standards do not exist to assess one's competency, which can make the process subjective (McGowan, 2011). Similar recent state legislation in Oregon and Washington provide individuals with the right to "death with dignity", in which individuals with six months or less to live can elect to be provided with lethal medication. The individual must be able to make the decision to take the medication for himself and must indicate an understanding that taking the medication will result in death (Richardson, 2010). The Oregon and Washington laws were established to eliminate unnecessary suffering and to provide individuals with terminal illnesses the choice of when to die (Richardson, 2010). This right is available to people who are of "sound mind" and who have the "ability to make and communicate health care decisions to health care providers, including persons familiar with the person's manner of communicating if those persons are available" (Oregon Death With Dignity Act, 2011). "Death with dignity" laws have been met with much debate and opposition, however, in that the laws provide terminally ill individuals the opportunity to determine if or at what point disability and illness become so unbearable that it is better to die. Moreover, concern exists about the potential abuses of such legislation by individuals with disabilities. Such legislation is an example of one of many pieces of law with notable relevancy to disabilities.

Health-related Technologies

Recent health-related technologies create a whole new range of ethical considerations not foreseen by previous generations (Muller, 2009). One such technology that has faced scrutiny from those concerned with disability rights is prenatal genetic testing. "Many discuss the imminent arrival of a new era of eugenics, and some disability rights groups have even compared genetic innovations, especially genetic testing coupled with abortion, as a form of cultural or minority group genocide" (O'Brien, 2011, p. 349). Furthermore, in a society such as the United States that has the ability to sustain life far beyond what could be expected without medical intervention, parents of children with severe disabilities must make difficult decisions in quick moments. Muller (2009) describes the birth of a child born with Down Syndrome and a blocked esophagus. The parents were given the choice of performing a life-saving corrective surgery on the child's esophagus or letting the child die. The parents came to the conclusion that allowing the child to die would be the best option. This decision became grounds for much outrage and debate about discrimination against individuals with disabilities, as the parents' decision suggested it was better to die than to have to live with a disability (Muller, 2009).

Cochlear implantation is another health-related technology that many individuals fear will have drastic consequences on the disability community. A large number of individuals who are deaf associate strongly with the Deaf community. Many argue that Deafness is a cultural group and that cochlear implantation, particularly in children, robs individuals of their culture (Sparrow, 2010).

> The signed languages Deaf people use are as fully-fledged and natural as spoken languages are. It would thus seem possible to question cochlear implantation and perhaps even argue that implantation is a form of forced normalization. If one can argue that prelingual deaf children belong in some way to a signed language and its culture, attempts to alter this belonging by means of surgery could be ethically questionable. (Kermit, 2009, p. 160)

As with genetic testing and selective non-treatment, cochlear implantation often requires parents, most of whom are not deaf themselves, to make the decision for their child. Thus, the dilemma requires deliberation to determine not only if the use of the technology is ethical in and of itself, but also if society's model of disability is ethical and just (Kermit, 2009).

Many argue that the use of health-related technologies has strong ethical implications. A background in disability studies and ethics allows students to understand the multiple perspectives at play when considering when and how such technologies should be utilized in healthcare and what consequences medical technologies may have for the disability community at large.

Population Composition

The changing population composition in the United States further necessitates a need for healthcare ethics education. One major change is a growth in racial and ethnic diversity (Shrestha & Heisler, 2011). Much of this increase in diversity can be attributed to immigration to the United States, which has increased not only the diversity of the nation, but has also played a role in increasing the overall size of the population (Shrestha & Heisler, 2011). For example, the number of Hispanic individuals in the United States is projected to reach approximately thirty percent of the population by the year 2050, with other minority groups growing substantially as well (Shrestha & Heisler, 2011). Linguistic and cultural differences may become increasingly notable in healthcare practice. Dilemmas relating to differences between what the practitioner believes to be the correct course of treatment and what the patient desires based upon cultural practices may become increasingly pertinent with more diversified patient populations. Linguistic barriers may also be grounds for ethical dilemmas, as communication between healthcare professionals and patients may become a struggle. Linguistic and cultural differences add another dimension to the ethical treatment of patients with disabilities.

CHAPTER III

Course Design

Once the need was established for an undergraduate disability studies ethics course, the next step was to begin designing a course to fill this void. Examination of literature relating to the design of such courses proved helpful in developing a foundation. It was important from the start that the course be interdisciplinary. Although the course will be taught by a faculty member from the Department of Speech Pathology and Audiology, a predetermined goal was that the course be relevant for any student. Interdisciplinary education is the process by which two or more disciplines work together to demonstrate the role of interprofessional relationships while also enhancing students' understanding of each discipline separately by, in the case of healthcare ethics, offering the opportunity to view the perspectives of different professionals (American Association of Colleges of Nursing, 1996, as cited in Stone et al., 2004). Healthcare ethics is a subject that fits well into a multidisciplinary framework of course design, because it is a topic that is relevant to all healthcare professionals (Stone et al., 2004), as well as potential patients and individuals from a broad range of professional goals. Because disability studies courses seek to examine the societal forces that shape the experiences of individuals living with a disability, the participation of students from a variety of disciplines outside of healthcare will be an asset to the course by providing unique perspectives on the topics. For example, an individual with an anthropology or history background may provide a perspective more focused on cultural practices associated with disability, whereas a pre-law student may provide a perspective focused on legal issues when making ethical decisions. Furthermore, because ethical decisions made by healthcare professionals will not always be made at the sole discretion of one individual, it is important to examine the perspectives of individuals from a broad range of healthcare professions and the interplay between such perspectives. Thus, an interdisciplinary approach to educating pre-professional healthcare clinicians helps meet the need of students soon to be entering collaborative practices (Larson, 1995, as cited in Stone et al., 2004).

Because of the cross-disciplinary focus of an ethics course, it was important to examine the perspectives of individuals from a variety of healthcare professions, as well as those in disability studies, education, special education, and other fields of study. Paramount in the perceptions of all associated professions was the duty of the professional to act in the best interest of the individual being served. What one views to be in the best interest of the individual being served, however, can differ greatly across professionals and patients. For example, in the book *The Spirit Catches You and You Fall Down*, the doctors believe that providing life-saving medical treatment, even if it means living in a vegetative state, is acting in the best interest of the patient. The patient's family, on the other hand, believe that the doctors should have abided by the health-related customs that their culture believes in, even though their daughter may not have survived (Fadiman, 1997). Codes of ethics across various professions do not necessarily provide straightforward guidelines on judging the best way to handle ethical situations. A course such as the one being proposed will provide students with a more well-rounded perspective on a variety of issues relating to healthcare and disabilities, which will aide in the ethical decision-making process.

Because the course is designed with the intention of being included in a Disabilities Studies minor and part of a liberal education foundation, it was also important to keep in mind the framework under which the course should fall. For inclusion in the Disabilities Studies minor, the course needed to provide students with an understanding of how societal forces, such as politics, art, education, and philosophy, affect and create the experience of being a person with a disability (Miami University Department of Sociology and Gerontology, n.d.). For inclusion as a social science course for the institution's liberal education foundation, demonstration of the principles of thinking critically, understanding contexts, engaging with other learners, and reflecting and acting were necessary (Miami University Office of Liberal Education, n.d.). The course was easily categorized as a social science because the object of the course was to examine the relationship of individuals with disabilities to their healthcare professionals, to their social and ethnic groups, and to their society and culture as a whole.

From the beginning, the course was conceptualized as being a seminar-style class rather than a lecture format. The topic of ethics lends itself well to a class based primarily on inquisition, critical thinking, and discussion, which also correlate with the liberal education foundation requirements. The way the course has been formatted, students will be required to read a variety of articles and books, listen to archived radio broadcasts, and watch documentaries and movies, critically examining each for biases, identifying ethical decisions present in each situation or story, noting the stakeholders in each decision, debating the varying perspectives in each situation, and ultimately coming to an informed decision on their views of the situation. It is important that students have the opportunity to consider the social pressures and values into which they have been socialized, and how those pressures impact their ethical decision-making (Matchett, 2008).

Because the topic of ethics and disability is extremely broad, the course is divided into three sub-sections of focus, which were based upon common themes found across a variety of materials examined for inclusion in the course. The three broad topics the course will cover are medical decisions, the role of community, and care. The medical decisions section will examine topics such as consent, prenatal genetic testing and selective pregnancy termination, physical alteration of the body, and cultural or linguistic differences that may affect one's ability to make informed decisions regarding healthcare. The section covering the role of community will examine how different groups of individuals with disabilities have shaped perceptions of ethical issues relating to the specific disabilities. For example, one week will be spent looking at Deaf culture and the ethical dilemmas surrounding cochlear implantation. Another week will be spent examining mental illness. One area of concentration will be the "mad pride" movement, which contradicts the ideology of many professionals in the field of psychiatry that pharmaceutical treatment is a necessary component of managing mental illness. The section focusing on care will cover a variety of topics including chronic illness as a form of disability, the right to "death with dignity", long term care options for young individuals, and children as caregivers for chronically ill or disabled parents. Although it would be impossible to include everything related to ethics and disability, these three sub-groups and the variety of information presented under each will yield an understanding of many of the present ethical dilemmas in healthcare for individuals with disabilities. Upon completion of the course, students will be able to make informed decisions about related legislation and demonstrate a greater understanding of how emerging healthcare technologies and disability rights movements can and may affect them as well as individuals with disabilities. Furthermore, they will have a greater understanding of the process of ethical decision-making, particularly as it relates to dilemmas involving disabilities.

In deciding upon assignments for the course, it was important to keep in mind that the primary goals for the course were critical thinking and dialogue with other learners in regards to the various ethical considerations examined. Thus, assignments and class activities needed to be reflective of these same goals. Examination of a variety of media selections comprises a major portion of course assignments. For each of the sub-sections of the course, medical decisions, the role of community, and care, a book will be assigned as a major case study for the particular section (Appendix A). The class will be divided into three groups, with each group reading and presenting on a different book; other related articles, archived radio broadcasts, and documentaries will be reviewed by all students for class discussion. In terms of the book assignment, each group will have the opportunity to choose from several creative projects, including wikis, videos, or podcasts, which they will use to present the book to the class and lead a subsequent discussion with their peers in which all class members will be expected to participate. Depending on the type of project created, the project may also be published to the Internet for the opportunity to share findings with the broader global community.

Blogging will be another component of the course structure and will be used as a means of reflection throughout the course and transfer across topics. Because of the difficult nature of some of the topics covered in the course, it will be important for students to have an outlet to express their reaction to the materials. Furthermore, blogging will allow student-to-student interaction, teacher-to-student interaction, and potentially even the dissemination of ideas to a broader audience via the Internet, which could not be achieved through in-class written assignments. Students will complete one blog post each week from two possible options. Students can choose to give their thoughts on specific questions outlined by the instructor or explore a link to a resource provided by the instructor and give their thoughts on the helpfulness of the resource. At the end of the post, the student should also write at least one paragraph describing their reaction to the week and any questions that they have in regards to course readings, assignments, or discussions.

Lastly, students will complete an independent final project, examining and critically thinking about an ethical dilemma relating to a population of individuals with disabilities.

Students will choose their own topic, which may not have been covered in class. A list of suggestions will be provided, although students may choose something not on the list as well. The final project may take any form the student chooses: a student-created multimedia piece, such as a video or a podcast, a wiki page, or a traditional research paper, as long as the project fully and extensively covers the required concepts. The project will consist of three parts: first, a thorough description of the population being examined and the ethical dilemmas existing, second, a description of all stakeholders and their perspectives in regards to the issue, and third, the student's own opinion on the issue. A public presentation or poster session at the end of the semester may allow for dissemination of ideas to a broader audience.

Throughout the course design process, not only was it necessary to keep in mind the goals of the course, but it was also necessary to continually relate the structure of the course and the chosen activities and assignments back to the guidelines for liberal education courses. As previously stated, the four principles of liberal education are thinking critically, understanding contexts, engaging with other learners, and reflecting and acting. These principles are evidenced in the course in the following ways:

> *Thinking Critically:* The course will require students to think critically about ethical considerations that healthcare professionals working with individuals with disabilities may need to take into account. Students will have the opportunity to think critically by completing a variety of projects such as blog posts, wiki pages, and a term paper/project in which they are asked to examine an issue and perspectives and then formulate their own opinion. Critical thinking will also be practiced through class discussions.
>
> *Understanding Contexts:* One of the primary objectives of the course is to allow students to gain an understanding of how different contexts influence one's perception of ethical

dilemmas. Readings will emphasize how different models of disability and the contexts surrounding these models can influence perspectives on ethics. Cultural and ethnic diversity and changes in demographics in the United States will be discussed in relation to providing ethical healthcare.

Engaging with Other Learners: The course is highly collaborative in nature. The seminar-style class will require that students engage in discussion and drive the direction of the course. Students will also work collaboratively out of class to complete a group project.

Reflecting and Acting: The conclusion of the course will require students to act upon what they have learned and research topics of particular personal interest. A final term paper or project will require students to present a case study of a real ethical dilemma in healthcare relating to individuals with disabilities. A discussion of all stakeholders and notation of resources that the various groups, including the professional, could use to make an ethically sound decision in regards to the issue will be included. Projects created in the course may also be published to the Internet for sharing with the broader community, allowing students to take action in raising awareness regarding ethical considerations when working with individuals with disabilities.

CHAPTER IV

Selection of Course Materials

As previously discussed, a large component of creating this course was reviewing materials for potential inclusion. During the review process, several common themes emerged. These themes were medical decisions, the role of community, and care, which became the three major sub-sections of the course. Thus, all of the readings and other forms of media included in the course were finalized based on the goal of enhancing students' understanding of these three themes.

Prior to beginning the three sections, a short overview of ethical theory and disability studies will allow students to gain the necessary framework for examining the ethical dilemmas that will be covered during the course. In addition, students will have the opportunity to examine codes of ethics from a variety of professions and organizations. Students will determine similarities and differences across the codes, in addition to identifying biases. Gaining an understanding of disability studies, ethical theory, and ethical decision-making across disciplines will prepare students for perspective taking before they delve into the major content areas of the course.

Medical Decisions

The focus of the medical decisions section was to explore different ethical dilemmas that arise when electing to perform major medical procedures, specifically those that occur because of variance between the view of healthcare professionals and the view of patients with disabilities or the families of patients. Topics covered in this section include issues relating to consent, prenatal genetic testing, physical alteration of the body, and multicultural views on Western medicine. Many of these topics are related in that they require examination of the ethicality of medical technologies. Medical technologies are a focal point in healthcare ethics, as they have changed the face of medicine in recent years (Muller, 2009).

Several articles included in the course deal with the ethical considerations associated with performing a potentially life-altering surgical procedure on a six-year-old girl, Ashley (Burkeholder, 2007; Dahlstrom, 2007; Gibbs, 2007). Ashley had a severe disability including brain damage and received medical treatment in 2004 to stunt her growth and remove her uterus and breast tissue. Her parents came under scrutiny as people questioned whether the parents had the procedure performed for their own convenience or for the benefit of their daughter (Gibbs, 2007). Her parents argued that stunting her growth would allow the family to include Ashley more easily in everyday activities, which would contribute to her quality of life. The removal of her uterus and breast tissue was performed to make her more comfortable, particularly post-puberty, and would also eliminate the possibility of breast cancer or fibrocystic disease, both of which run in her family (Gibbs, 2007). A hospital ethics board was responsible for reviewing the parents' request prior to the procedure to ensure that the treatment was ethically sound (Burkholder, 2007). The three articles, *Pillow Angel Ethics*, *Doctor at Center of Stunting Debate Kills Himself*, and *Ethicist in Ashley Case Answers Questions*, together provide an interesting look into the Ashley case. One of the three articles is written in a more informative manner, simply providing information about the situation. The second article is a transcription of an interview with one of the ethicists involved in evaluating the case prior to the procedure being performed. The third is a report about the suicide of one of the doctors who performed the surgery on Ashley. This set of articles is quite interesting in that it allows students to not only examine the ethical dilemma associated with the situation, but also brings to light the very real consequences of providing treatment.

As previously mentioned, each sub-section of the course contains a book assignment in which a group of students will be responsible for presenting to the class. The book selected for this section is *The Spirit Catches You and You Fall Down: A Hmong Child, Her Doctors, and the Collision of Two Cultures,* which tells the story of a young Hmong child with severe epilepsy. A major theme of this book is identifying the role that the Hmong culture played on the desires of the young child's family in regard to her medical treatment, and how their desires differentiated from the treatment provided by the American doctors. Of particular concern in this story was the linguistic barrier between the healthcare professionals and the Hmong family. Major medical decisions were made without being able to provide the family members with a clear explanation of the procedures that were to be performed and obtaining consent also became problematic (Fadiman, 1997). Cultural differences also make medical decisions particularly difficult. In this case, the Hmong people, with a long history of persecution, are distrustful of anyone but other Hmong. Furthermore, they practice very specific cultural traditions relating to birth, death, and healthcare generally; when violations of customs are being considered, which often occurs when the Hmong utilize American hospitals, involvement of the entire community is necessary to make such a decision (Fadiman, 1997).

> Decisions—especially about procedures, such as surgery, that violated Hmong taboos—often took hours. Wives had to ask their husbands, husbands had to ask their elder brothers, elder brothers had to ask their clan leaders, and sometimes the clan leaders had to telephone even more important leaders in other states. In emergency situations, the doctors sometimes feared their patients would die before permission could be obtained for life-saving procedures. (Fadiman, 1997, p. 71)

As can be seen, the culture and language of an individual can have a profound impact on their decision-making process in regards to healthcare.

The Role of Community

The role of community was selected as a focus for the course because of the growing group identification within specific disability groups in recent years and the subsequent influence on healthcare ethics. Deafness, for example, is one disability in which individuals have a defined cultural group with specific norms, expectations, customs, and ideologies. Deaf culture has greatly impacted the ethicality of cochlear implantation. Many healthcare professionals and hearing individuals view cochlear implantation as a technology to be celebrated, while many Deaf individuals who strongly associate with Deaf culture view cochlear implantation as a threat to sign language and their culture in general. Thus, the advent of cochlear implantation has resulted in a struggle between those in favor of the technology and those who decry it. Although perhaps less established than Deaf culture, several other disability culture groups have grown in size and strength in recent years. Materials selected for inclusion in the role of community section of the course include articles on the role of community for individuals who are blind, Deaf, mentally ill, and Autistic.

A particular focus for this section is exploration of the role of community among individuals with mental illness. A book, an article, and a documentary have been included in this section to highlight the ways in which "mad pride" affects ethical decision-making in healthcare. The article, entitled *Listening to Madness*, describes the "mad pride" movement, in which individuals with mental illness have come to celebrate their unique ways of looking at the world. Many individuals who use medication to treat their mental illness feel that they are suppressed by the pharmaceuticals they take. They would rather deal with the difficulty of living with extreme emotional states than lose their "dangerous gifts" ("Listening to Madness", 2009). Many of these individuals practice forms of alternative medicine to try to limit their extreme emotions. They feel as though the distinction between normal and mentally ill is too arbitrary and that limiting individuals through pharmaceutical usage eliminates mental diversity ("Listening to Madness", 2009).

Another resource, a documentary by director Ken Paul Rosenthal and producer Angel Vasquez, entitled *Crooked Beauty*, explores the experience of an individual with mental illness and her involvement in the Icarus Project, a so-called "mad pride collective" that celebrates mental uniqueness (Vasquez, 2010). In this documentary, the individual, Jacks Ashley McNamara, discusses how identifying with the Icarus Project community allows her to better recognize her identity as a human being rather than as a person with a disability. She states:

> There are stages in the formation of our identity where it's extremely empowering to own the part of us that society marginalizes and say there's nothing wrong with that part. And then I think there are also times when we can move beyond those definitions. I'm less and less identifying as a "mad person" or a "liberated mad person" and am identifying more as a person who is traumatized by her life experience just like so many other people. (Vasquez, 2010)

The documentary stresses that the community surrounding mental illnesses is also important in breaking the stigma associated with mental illness, instead fostering an association between mental illness and courage, value, and strength. This documentary puts a face on mental illness the community surrounding mental illness.

Another resource for the community section is the book, *Voluntary Madness: My Year Lost and Found in the Loony Bin*, by Norah Vincent, which provides a different perspective on community. *Voluntary Madness* is a first-hand account of being admitted to and spending time in three different rehabilitative programs for individuals with mental illness. The first was a mental ward in an urban, public hospital, the second, a small, quiet facility with a religious affiliation, and the third, a spa-like therapy facility that minimizes medication usage and promotes activity, exercise, and play as a means of therapy. Although Vincent checks herself into the various programs as an undercover journalist, she does indeed suffer from depression. Within her writing, she not only makes observations of her fellow patients and healthcare professionals with whom she comes into contact, but also of her own transformation (or, in come cases, lack thereof), during her stay at each institution. *Voluntary Madness* enhances students' understanding of the role of community by providing a perspective unique to the other two sources on mental illness. The community that helps Vincent come to terms and improve her quality of life as she battles with depression is the community she finds within the various healthcare facilities. Vincent leaves readers with divergent views of psychiatric facilities and the associated healthcare professionals. Some leave much to be desired, while others provide a great deal of care and support to patients. However, it is up to the patient to enter with an open mind and a desire to put in effort (Vincent, 2008). For Vincent, the sincere and honest relationship with her therapist and the other healthcare professionals at the last facility allowed her to open up about her depression and make progress in gaining a greater understanding of how her thoughts and actions relate back to her troubled past. The community at the last facility was based upon the ideals that individuals with mental illness deserve respect, understanding, compassion, and effort on the part of healthcare professionals. Vincent asserts that these ideals, in part, allowed her to thrive in this community (Vincent, 2008).

Listening to Madness, *Crooked Beauty*, and *Voluntary Madness* will provide students with a view of mental illness from an insider's perspective. It is hoped that these resources will prompt students to explore a broad variety of topics within the realm of healthcare ethics relating to mental illness and how the ethical decision-making process might be influenced by the role of the "mad pride" community. For example, students might wonder about the responsibility of a professional who is reasonably concerned about a patient harming himself or others should he stop taking medication. How should the professional and the patient opinions be balanced? With a building role of "mad culture", does the role of the professional change to support the needs of patients who celebrate their unique perspectives? In conjunction with the use of the aforementioned resources and subsequent class discussions, a mental health professional will be sought to lead a discussion to provide students with the opportunity to engage with someone who is outside of the patient role. Such a discussion will further enhance students' ability to consider differing perspectives, aligning with course objectives, disability studies program goals, and Miami Plan goals.

The themes found in the materials relating to mental health are examples of similar themes found in materials that have been included in the course that relate to other communities. It is hoped that students will be able to compare and contrast the community influence on healthcare ethics across a variety of disability groups.

Care

The third and final sub-section of the course is care. Materials included in this section will enhance students' understanding of various implications relating to long-term care and end-of-life decisions for individuals with disabilities. Topics include nursing home care for the young, children as caregivers for parents with disabilities, chronic illness as a form of disability, and the right to "die with dignity" movement.

Several interesting ethical situations arise when examining the living arrangements of individuals with disabilities. For example, one article, *A New Nursing Home Population: The Young*, examines how it is becoming increasingly common for young individuals with severe disabilities to be admitted to long-term nursing home care. States are required by federal law to pay for nursing home care for individuals with disabilities, but current legislation does not mandate states to cover the costs of in-home attendants to provide individualized care. Individuals who would reap benefits from such a mandate argue that having to live in a nursing home has significant consequences on an individual's quality of life (Shapiro, 2010). Of the young individuals living in nursing home care, many have never lived on their own. Others have children and thus, the entire family unit is affected if a parent requires nursing home care. In addition, socializing is difficult for a young individual in a care facility primarily for older adults. Individuals with severe disabilities are pushing for states to provide in-home attendant care; however, the added cost and limited workers would put a definite strain on state budgets (Shapiro, 2010). Several ethical dilemmas arise from this reading. Do individuals with severe disabilities who depend on state-funded nursing care have the right to decide where to live? Should there be criteria, such as having children or other dependents, to determine who receives funding for in-home care?

Another ethical concern related to the long term care of individuals with disabilities deals with child caregivers. A perhaps neglected group in research and in advocacy is the population of children under the age of eighteen who serve as caregivers for chronically ill or disabled parents or grandparents. Of the approximately 1.3 million child caregivers in the United States, most come from lower income, single parent families and often take on the role of a home health aide (Levine, 2009). Dealing with such a large responsibility can yield highly negative consequences for these children, including difficulty at school, feelings of anger or frustration for not having a "normal" childhood, and isolation from peers. While respite programs exist, such programs often neglect young caregivers. Documentation of programs targeting young caregivers exists in the United Kingdom and Australia; however, such programs have come under scrutiny because of concern over whether child care-giving is an ethical practice (Levine, 2009; Belluck, 2009). The article cites a variety of ethical issues relating to children providing care to disabled or chronically ill relatives:

> What are appropriate responsibilities for children of different ages, abilities, relationships with parents or grandparents, cultural backgrounds, and other factors? Are there duties that should never be assigned to child caregivers? What is the line between parental choice and abuse and neglect? When a child expresses frustration or anger towards a vulnerable parent, what is the appropriate response? How does a program to help children who have taken on the care-giving role balance respecting parent rights and needs and advocating for children? (Levine, 2009)

The article provides an interestingly look at a care-giving situation that is not often explored and suggests that ethical dilemmas involving disabilities may not always only involve the individual with the disability but may also involve other people in the individual's lives.

The book chosen for this subsection of the course was *Sick Girl*, written by Amy Silverstein, which discusses the author's diagnosis of congestive heart failure at the young age of twenty-four. Silverstein, a driven law student, finds that her life changes dramatically upon receiving the diagnosis; as her symptoms progressively worsen, she becomes more and more debilitated by her disease (Silverstein, 2007). The book is compelling in that it provides students the opportunity to explore chronic illness and the need to be cared for through the eyes of a person roughly their own age. Of particular interest is that one does not necessarily pity the main character. The book is written as an autobiography, so readers gain an understanding of Silverstein's thoughts and deliberations, which are sometimes selfish or ugly. This writing style puts readers into the situation, allowing them to understand what it is like to live with a chronic illness and make assertions about care and disability for themselves.

Once again, the sources discussed in this section are examples of the many resources reviewed and selected for inclusion in the course syllabus. It is hoped that these works will provide students the opportunity to examine a broad range of ethical dilemmas associated with various disabilities and healthcare practices.

CHAPTER V

Personal Reflection: A Student's Perspective on Curriculum Design

The process of designing a course for inclusion in an undergraduate pre-health and disability studies curriculum has truly been an empowering and thought-provoking experience. The idea for this project began when my professor mentioned in casual conversation that she had previously taught a course on medical ethics some time ago and would like to create a course with similar goals in mind but with a focus on disabilities. I asked if I could be a part of the creation of this course, collaborating and providing a student's perspective. This project was very appealing to me, as it provided the opportunity to explore a portion of the world of academia. Recently, I have contemplated the idea of eventually pursuing a career as an academic. Creating a course has allowed me to have first-hand experience in designing a curriculum, immersing myself in a part of the academic world that few have the opportunity to venture into as an undergraduate student.

The first step in creating the course was to engage in a dialogue with my supervising professor, who was able to provide me with a starting point in researching and reviewing materials. Together, we brainstormed a long list of possible topics for inclusion, and from there, I was able to use Internet search engines, peer reviewed article database searches, and investigation at my institution's libraries to examine the available resources for the topics on our list. I began to read, watch, and listen to the books, documentaries, movies, and archived radio broadcasts that I came across, weeding out those less relevant to the theme of disability and ethics and noting those that could potentially add something to our course. I found that while many of the resources dealt with disability or ethics as two separate entities, there were fewer that dealt with the interplay between the two topics. I realized that my goal was to find resources that connected the two entities or could be used in conjunction with one another to yield exploration of ethical dilemmas at hand in situations dealing with disabilities. While some sources blatantly discussed ethical dilemmas relevant to disabilities, others were subtler, requiring a disability studies lens through which to view the situation. Both proved valuable and were considered for inclusion in the course.

One major point of concern from the beginning of the project was to make sure that the course was unique from other courses offered at the institution. Early on, I considered starting the course with an examination of the historical development of ethics, in which students would have the opportunity to delve into philosophical frameworks. Some time would then be spent on medical ethics, examining topics such as the Hippocratic Oath and effects of its present interpretation. The final focus of the course would be ethical issues one might encounter while working with individuals with disabilities. Upon reviewing the syllabi of other healthcare-related courses at the institution, however, I decided that perhaps a better way to start the course would be to provide students with an understanding of disability studies, as the unique feature of our course was indeed the focus on disabilities. Although time will still be spent investigating theories of ethics and examining ethical codes, a disability studies lens will be utilized in this process. For example, a key point will be to critique codes of ethics from a variety of disciplines, identifying bias and potential shortcomings of each code. One thing that proved very helpful in coming to this conclusion was developing the course objectives. My faculty supervisor urged me very early on in the process to write out my goals for the course. Although the goals changed throughout the process, having my objectives in print helped me identify the ways in which the course could be unique and also how I might structure the course to fit those goals. My objectives for students completing the course were as follows:

- Describe the components of an ethical dilemma.
- Discuss ethical considerations that should be taken into account when working with individuals with disabilities and critically evaluate implications of decisions.
- Identify social forces that impact the experience of having a disability and discuss the role of these social forces in relation to ethical dilemmas and decision-making.
- Describe multicultural variation in perceptions of ethics regarding populations of individuals with disabilities.
- Identify resources utilized by healthcare professionals working with individuals with disabilities to aid in the process of ethical decision-making.
- Identify bias and position within editorial works and assess validity of sources.
- Identify and describe multiple perspectives present in a given ethical dilemma.

Upon writing out what skills I would like the course to foster, I was better able to recognize not only how to structure the course, but also which sources would further the objectives of the course. Thus, the declaration of my goals for the course was an integral part of establishing a basis for the course.

An obvious personal learning outcome of this project has been a significant increase in my knowledge of ethics, disabilities, and the intersection between the two. The amount of reading I have completed in the process of designing the course yielded a greater understanding of these topics. All of the works selected for inclusion were chosen because they offered a perspective on ethics and disability that would likely be challenging to the perspectives of many students in the course and would thus yield debate and dialogue between members of the class. I was personally affected by many of the resources reviewed. In particular, the documentary *Crooked Beauty* challenged me to change my perspectives on mental illness. Prior to reviewing this film, I viewed mental illness as a medical problem that required treatment. I had read articles and seen news segments about destructive criminal offenses performed by individuals suffering from mental illnesses, so I believed mental illness to be a medical condition that required pharmaceutical treatment. To be perfectly honest, I felt a somewhat negative connotation towards mental illness. This film, however, significantly changed my opinion. I now recognize that pharmaceuticals can potentially have a negative effect on the quality of life of an individual. Individuals with mental illness often feel stifled by their medications, and many value having a mind that thinks and feels differently than what is considered "normal". Through careful self-regulation, individuals with mental illness can live safely without pharmaceutical intervention. While I still do not believe that such an approach would be ideal for every individual, I have a much more open-minded perspective on mental illness.

My perspectives were also challenged through reviewing the materials associated with chronic illness and end-of-life care. *Sick Girl* challenged me to consider chronic illness as a form of disability. Towards the end of the book, the author describes being on vacation with a large group of friends. She feels tired and miserable each day because of the fatigue and pain that her heart condition cause her, yet her friends and husband do not realize the struggle she faces to participate in the full days of activities. Her chronic heart condition could be described as a hidden disability. I found many parallels between her experiences and the experiences of individuals with other types of hidden disabilities, such as hearing impairment, visual impairment, or learning disabilities.

Another selection related to chronic illness that prompted me to shift my perspective was the documentary *How To Die In Oregon*. This work was included in the course to prompt a discussion about the potential abuse of assisted suicide with populations that are elderly or disabled and to achieve a meaningful connection between disability and end-of-life issues. I was very deeply affected by *How To Die In Oregon*. The documentary was very emotionally driven, and I was surprised to find that by the end of the film, I was in favor of the "right to die with dignity" movement. For the individuals featured in the film, having the ability to control when they die was very comforting at a time when their lives were dominated by uncertainty. Although I am concerned about how assisted suicide legislation may impact individuals with disabilities, I believe that giving individuals who have little time left to live the opportunity of choosing when to die can be a positive option.

Several materials did not change my opinion but rather enhanced my present perspective on an ethical dilemma. One such material was *The Spirit Catches You and You Fall Down*. The selection allows readers to gain a greater understanding of ethical implications in healthcare settings that may occur as a result of linguistic and cultural differences between the healthcare practitioner and patient, and how such implications may be particularly pronounced in populations that are more prone to serious health conditions such as individuals with disabilities. I was already aware of the existence of dilemmas associated with consent, communication, and cultural beliefs and values, and I believe whole-heartedly that, particularly in areas with large populations of specific cultural groups, professionals of any kind should be knowledgeable about the customs of the particular culture. In healthcare settings in particular, at the very least there should be someone who is able to communicate fluently in the language to be able to explain necessary medical information and gain consent for procedures. *The Spirit Catches You and You Fall Down* enhanced my understanding of ethical dilemmas relating to language and culture, by providing concrete examples of instances in which not having individuals well-versed in the language and culture of a patient resulted in significant consequences for both the patient and family and for the healthcare professionals.

I also attribute a great deal of my learning to the experience of critiquing works for inclusion in the course. I had the unique opportunity in this project to examine works from a variety of perspectives: as a student, as a teacher, as a disability studies scholar, and as a future healthcare professional. Obviously, first and foremost, I am a student. I entered into this project with the mindset that I would be creating a course suitable for my peers. I wanted a class that would be engaging and interesting for students, something that I would enjoy myself as an undergraduate, so I utilized my perspective as a student to drive many of my decisions in regard to the course. This project also necessitated that I work from the perspective of a teacher. I had to think about the best ways to engage students, while also meeting the educational outcomes that I set for the course. I had to conceptualize various modes of assessment and determine which would fit best with the goals of the class. It was necessary for me to also think like a disability studies scholar. I needed to model the course in a way in which students would gain an understanding of the forces that shape the experience of disability and in which students would be called to move away from a medical model of disability. Lastly, I needed to use my perspective of a future healthcare clinician to create a class that would provide knowledge that could meaningfully be applied to real-life situations. Critiquing materials for inclusion in the course from all of these perspectives has changed the way I look at pieces of media, whether literary, scholarly, or creative works. I am better able to consider multiple perspectives and stakeholders in any given situation, and I can pinpoint biases. I have a greater understanding of how society shapes a given situation, not just the involved individuals. I am grateful that I have had the opportunity to intersect these different perspectives.

By far the most exciting aspect of creating this course, however, has been seeing all of my work come together in a completed syllabus. I am delighted that future students will be able to learn from the curriculum that I played a role in creating, assuming that the institution approves the course. I think that the curriculum designed over the past two semesters is unique and appealing in that it was designed in part from a student's perspective. Having collaborated with my supervising professor, I believe that we have created a course that is all-encompassing. It offers students activities and readings that are interesting and engaging, the opportunity to choose topics and formats for projects that are personally appealing, and a seminar-style class that will be driven primarily by student discussions and interests. At the same time, it also meets the needs of the instructor, in that it provides a variety of forms of evaluation, including blog posts, book projects, and final projects. Furthermore, by providing students with choices in the projects they create, it adds variety for the instructor and will make teaching the course a more engaging experience. I could not be happier with the final product and look forward to hearing about students' experiences taking the course in future semesters.

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APPENDIX

Appendix A: Syllabus

Healthcare Ethics and Disability
SPA 000
Fall 2012

Class Time:
Instructor:
Email:
Phone:
Office Hours:
Office Location:

COURSE DESCRIPTION

Students will examine present day ethical dilemmas of healthcare professionals working with individuals with disabilities. Emphasis will be placed on understanding the various social forces that impact ethical healthcare practices with particular regard to disabilities. Students will utilize a variety of technologies to discuss and share their thoughts and opinions both individually and cooperatively using wikis, podcasts, blog posts, etc.

COURSE OBJECTIVES

This course is designed to provide students with an understanding of ethical considerations pertinent to the treatment and care of individuals with disabilities. After completing this course, students will be able to:

- Describe the components of an ethical dilemma.
- Discuss ethical considerations that should be taken into account when working with individuals with disabilities and critically evaluate implications of decisions.
- Identify social forces that impact the experience of having a disability and discuss the role of these social forces in relation to ethical dilemmas and decision-making.
- Describe multicultural variation in perceptions of ethics regarding populations of individuals with disabilities.
- Identify resources utilized by healthcare professionals working with individuals with disabilities to aid in the process of ethical decision-making.
- Identify bias and position within editorial works and assess validity of sources.
- Identify and describe multiple perspectives present in a given ethical dilemma.

WHERE THIS COURSE FITS IN THE MIAMI PLAN

This course fulfills requirements for the Miami Plan Foundation IIC, as a social science foundation course (pending approval). The course can also be used to satisfy requirements for the minor in Disability Studies (pending approval).

MIAMI PLAN PRINCIPLES

The four principles of Liberal Education are thinking critically, understanding contexts, engaging with other learners, and reflecting and acting. These principles will be evidenced in the course in the following ways:

> *Thinking Critically:* The course will require students to think critically about ethical considerations that healthcare professionals working with individuals with disabilities may need to take into account. Students will have the opportunity to think critically by completing a variety of projects such as blog posts, wiki pages, and a term paper/project in which they are asked to examine an issue and perspectives and then formulate their own opinion. Critical thinking will also be practiced through class discussions.
>
> *Understanding Contexts:* One of the primary objectives of the course is to allow students to gain an understanding of how different contexts influence one's perception of ethical dilemmas. Readings will emphasize how different models of disability and the contexts surrounding these models can influence perspectives on ethics. Cultural and ethnic diversity and changes in demographics in the United States will be discussed in relation to providing ethical healthcare.
>
> *Engaging with Other Learners:* The course is highly collaborative in nature. The seminar-style class will require that students engage in discussion and drive the direction of the course. Students will also work collaboratively out of class to complete a group project.
>
> *Reflecting and Acting:* The conclusion of the course will require students to act upon what they have learned and research topics of particular personal interest. A final term paper or project will require students to present a case study of a real ethical dilemma in healthcare relating to individuals with disabilities. A discussion of all stakeholders and notation of resources that the various groups, including the professional, could use to make an ethically sound decision in regards to the issue will be included. Projects created in the course may also be published to the Internet for sharing with the broader community, allowing students to take action in raising awareness regarding ethical considerations when working with individuals with disabilities.

COURSE STANDARDS

Class attendance is a requirement and students will be docked participation points after the student's second unexcused absence. Active participation is expected during every class and is part of the basis of evaluation of the course. Students should come to class prepared, having read and completed all assignments. Students should also come prepared to discuss course topics and materials.

Students requiring accommodations are responsible for communicating those needs to the instructor. Furthermore, if students are experiencing problems or have questions about any aspect of the course, please communicate those concerns to the instructor so the concerns may be alleviated.

Academic misconduct will not be tolerated. Students violating rules of academic conduct will be subject to the penalties outlined in the Student Handbook, in addition to possible failure of the course. Please see *The Miami Bulletin Student Handbook*, Undergraduate Academic Regulations, Part V for details regarding plagiarism and academic misconduct.

GRADING

Evaluation

Blog posts	70 points (5 pts. X 14)
Book project	50 points
Final project/paper	100 points
Participation	80 points (50 pts. X 2)
Total	300 points

ASSIGNMENT DESCRIPTIONS

Group Book project: Students will be responsible for reading one of the three assigned books and completing a collaborative creative project of the group's choosing during the course of the semester. Possible formats could include wiki pages, videos, podcasts, etc. and should be approved by the instructor before beginning. Groups and deadlines will be assigned during the first week of class. Projects should first identify and describe the ethical dilemma. Next, each stakeholder should be identified (i.e. individual with disability, parent, spouse, doctor, pharmaceutical companies, insurance companies, etc.) and the stakeholder's perspective should be outlined. Finally, the group should provide their own opinion on the topic. The group should also incorporate other related course readings and outside resources to improve the quality of the discussion. 10 points of the grade will be given for the appearance of the project and 40 points will be given for content, based upon the rubric provided (50 points total).

Blogs: Blogs will be used as a means of reflection throughout the course and transfer across topics. Students will complete one blog post each week given two choices. Students can choose to give their thoughts on specific questions outlined by the instructor or explore a link to a resource provided by the instructor and give their thoughts on the helpfulness of the resource. At the end of the post, the student should also write at least one paragraph describing their reaction to the week and any questions that they have in regards to course readings, assignments, or discussions. Each post will be worth 5 points (3 points for questions or link; 2 points for reflection).

Final Project: Students will complete an independent final project, examining and critically thinking about an ethical dilemma of their choice relating to healthcare and disabilities. Students will choose their own topic, which may not have been covered in class. A list of suggestions will be provided; students may choose something not on the list as well. The final project may take any form the student chooses: a student-created multimedia piece, such as a video or a podcast, a Wiki page, a traditional research paper, etc. The instructor must approve all topics and project types. Preference will not be given to a specific type of project; each project must fully and extensively cover the required concepts. A rubric will be provided prior to evaluation. The final project will be worth 100 points.

The project will consist of three parts: first, a thorough description of the population being examined and the ethical dilemmas existing; second, a description of all stakeholders and their perspectives in regards to the issue; third, the student's own opinion on the issue. A minimum of six sources should be utilized to complete this assignment.

CLASS SCHEDULE

Week 1: Introduction to Course. What is Disability Studies? What is Ethics?

Video: Adichie, C. (2009, July). The Danger of a Single Story. *TedGlobal 2009*. Video. Retrieved from http://www.ted.com/talks/lang/eng/chimamanda_adichie_the_danger_of_a_single_story.html

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Blog post 1 due on Friday

Week 2: What is Ethical Decision-Making? Comparing and Contrasting Codes of Ethics?

Research and review a code of ethics from a field associated with disabilities (Ex. American Medical Association, American Speech Language and Hearing Association, American Nurses Association, National Education Association, etc.). Please print and bring to class.

Blog post 2 due on Friday

Weeks 3-6—Medical Decisions

Week 3: Physically Altering the Body

Burkeholder, A. (2007, January 11). Ethicist in Ashley case answers questions. *CNN.com International*. Retrieved from http://edition.cnn.com/2007/HEALTH/01/11/ashley.ethicist/index.html

Dahlstrom, L. (2007, October 11). Doctor at center of stunting debate kills himself. *MSNBC.com*. Retrieved from http://www.msnbc.msn.com/id/21225569/ns/health-health_care/t/doctor-center-stunting-debate-kills-himself/

Gibbs, N. (2007, January 7). Pillow angel ethics. *Time*. Retrieved from http://www.time.com/time/nation/article/0,8599,1574851,00.html

Blog post 3 due on Friday

Week 4: Prenatal Genetic Testing

Muller, J. (2009). The New Parenthood and the Old Ambivalence about Disability: Baby Doe, Prenatal Testing, and Disability Rights. Student Prize Paper, 44, 1-68. Retrieved from http://digitalcommons.law.yale.edu/ylsspps_papers/44

Blog post 4 due on Friday

Week 5: Consent

Selections from Kurson, R. (2007). *Crashing through: A true story of risk, adventure, and the man who dared to see.* New York, NY: Random House.

Selections from Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures.* New York: Farrar, Straus and Giroux.

Blog post 5 due on Friday

Week 6: Ethnic, Cultural, and Religious Influences

Selections from Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures.* New York: Farrar, Straus and Giroux.

Blog post 6 due on Friday

Presentation by project group 1: Fadiman, A. (1997). *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures.* New York: Farrar, Straus and Giroux.

Weeks 7-10—The Role of Community

Week 7: Blind

Selection from Kurson, R. (2007). *Crashing through: A true story of risk, adventure, and the man who dared to see.* New York, NY: Random House.

Blog post 7 due on Friday

Week 8: Autism

Autistic and proud: A movement takes hold. (2008, June 2). *NPR.* Retrieved from http://www.npr.org/templates/story/story.php?storyId=91054523

Participation for first half of class evaluated

Blog post 8 due on Friday

Week 9: Deaf Culture

Kermit, P. (2009). Deaf or deaf? Questioning alleged antinomies in the bioethical discourses on cochlear implantation and suggesting an alternative approach to d/Deafness. *Scandinavian journal of disability research, 11*(2), 159-174. doi: 10.1080/15017410902830744

Sparrow, R. (2010). Implants and ethnocide: learning from the cochlear implant controversy. *Disability and society, 25*(4), 455-466. doi: 10.1080/09687591003755849

Blog post 9 due on Friday

Week 10: Mental Illness

Listening to madness: Why some mentally ill patients are rejecting their medication and making the case for 'mad pride'. (2009, May 1). *The Daily Beast.* Retrieved from http://www.thedailybeast.com/newsweek/2009/05/01/listening-to-madness.html

Selections from Vincent, N. (2008). Voluntary madness: My year lost and found in the loony bin. New York: Viking.
In class: Vasquez, A. (Producer), & Rosenthal, K. P. (Director). (2010). *Crooked Beauty* [Motion picture]. United States: Ken Paul Rosenthal.
Blog post 10 due on Friday
Presentation by project group 2: Vincent, N. (2008). Voluntary madness: My year lost and found in the loony bin. New York: Viking.

Weeks 11-14—Care

Week 11: Nursing Homes for the Young

Shapiro, J. (2010, December 9). A New Nursing Home Population: The Young. *NPR.* Retrieved from http://www.npr.org/2010/12/09/131912529/a-new-nursing-home-population-the-young
Blog post 11 due on Friday

Week 12: Children as Caregivers

Belluck, P. (2009, February 22). In turnabout, children take caregiver role. *New York Times.* Retrieved from http://www.nytimes.com/2009/02/23/health/23care.html?_r=1&scp=1&sq=children%20caregivers&st=cse
Levine, C. (2009, February 27). All in the family: Children as home health aides. *Bioethics Forum blog.* Retrieved from http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=3220&blogid=140&terms=disability+and+%23filename+*.html
Blog post 12 due on Friday

Week 13: End of Life and Palliative Care

Selections from Silverstein, A. (2007). *Sick girl.* New York: Grove Press.
Blog post 14 due on Friday
Presentation by project group 3: Silverstein, A. (2007). *Sick girl.* New York: Grove Press.

Week 14: Chronic Illness as Disability

In class: Richardson, P. D. (Producer and director). (2010). *How to die in Oregon* [motion picture]. United States: Clearcut Productions, Inc.
Blog post 13 due on Friday

Weeks 15-16—Bringing it all together

Week 15: In-class presentations of final projects

Week 16: In-class presentations of final projects

Participation for second half of class evaluated