

AB, cultural anthropology

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## Disabled Bodies as “Minority Bodies” in Theory and Practice

Title Justification:

“In *The Minority Body: A Theory of Disability*, Elizabeth Barnes offers a philosophy of disability, arguing that disability is a social construct and a way of being a minority. In her view, disability does not mean that an individual is necessarily worse off for their disability, but rather that they are a minority subject to oppression. This book was eye-opening for me and has shaped my own views on disability and the program of study I am proposing. The question that defines my program asks what could happen if this philosophy were widely adopted. I believe that the title refers nicely to this philosophy and to these questions. By beginning the title with “Disabled Bodies” I am foregrounding that the program is grounded in disability studies. I think the phrase “minority body” forces people to think about their own understanding of the word minority and of physical disability in general and thus drives further conversation.

Abstract of Proposed Program:

Physically disabled individuals are subject to the limits of their bodies, which are compounded by limits placed on them by society. With this in mind, I have designed a program rooted in the multidisciplinary field of disability studies and focused specifically on physical disability. The program’s central question asks how understanding disabled bodies as “minority bodies” might redefine their place in and reshape their experience of society. I address this question through four modules with associated learning objectives: (1) Understanding Disability: What does it mean to be disabled? (2) A Good Life: what is a meaningful (disabled) life? (3) Culture, Identity, and Inequality: How do culture, identity, and inequality interact to shape the experience of disability? (4) Representations of Disability: How can disability be represented in a way that aligns with the “minority body” theory? To answer these questions, I will take classes in a variety of disciplines including psychology, sociology, cultural anthropology, public policy, religion, and visual and media studies as well as nontraditional classes such as an independent study of works by disabled authors and a Bass Connections project on the intersections of race, justice, and disability.

List of Core Courses: See Attached

Long Range Plan: See Attached

Senior Capstone Project:

I envision a senior capstone project that takes the form of a significant qualitative research project, focusing on how stigma influences segregation of individuals who identify as disabled (and then further within those communities across different dimensions of disability) from individuals who do not identify this way (or do not until they experience a significant change in health status due to illness, accident, or age). Building from the modules, my current plan is to conduct oral history/ethnographic interviews with disabled individuals, nondisabled individuals, family and friends of disabled individuals, and other groups involved in caregiving, support services, and health research. Additionally, I see the possibility of a participant-observation dimension to such a project examining the way disabled individuals experience both everyday settings or those designed specifically for their access such as MDA camp. In order to focus the project I would likely concentrate on a specific subpopulation of disabled individuals.

Considering my background with and the preexisting relationships I have with individuals with muscular dystrophy, I would likely choose to work with this population. I like the idea of a longform photo essay including pictures of how society sees an individual paired with pictures or artistic representations of how the individual sees themselves and would like themselves to be seen. The project would be a collaboration with these individuals with all involved individuals benefiting from the project. Because of the nature of this project it would require IRB approval.

Personal Statement: See Next Page

My job at Muscular Dystrophy Association (MDA) summer overnight camp was to help young people have the experience of a lifetime. An experience where their use of wheelchairs and walkers was the rule, not the exception. As I watched first graders Cooper and Teddy splashing in the swimming pool, I'll never forget the joy I felt followed by a wave of anguish. I had achieved my goal, the camp's goal; they were having a ball. Problem was, this was the exception. The rule was going to be waiting for them in the outside world. And what could I do about that?

I couldn't take either home with me, the house I grew up in can't accommodate a wheelchair. The barriers aren't just physical though. Stigma can make socializing difficult. Capitalistic definitions of success and productivity effectively invalidate the lives and work practices of many disabled individuals. At MDA camp, where disability is the "norm," individuals accustomed to being ignored and unappreciated are included and respected. Kids who enter camp silent and disengaged transform one week later into chatty and assertive children. The camp touts the effect their spaces have on children's lives but what about after camp? I began to think about what effect inclusive environments could have over the course of these children's lives. If we agree that discrimination on the basis of race, gender, sexuality, ethnicity is wrong, how do we justify ongoing inequity in terms of disability? What are the barriers to fundamental inclusivity and how can these barriers be eliminated?

This forms the foundation for my program's defining question: How might understanding disabled bodies as minority bodies redefine their place in and reshape their experience in society? The minority body theory, derived from a book by disabled philosopher Elizabeth Barnes, rejects the notion that to be disabled is to be inherently worse off. Instead, and in line with the disability rights and disability pride movements, having a disabled body is a way of being a minority. Thus, disabled individuals face social oppression similar to, and potentially to a greater degree than, other minority groups. In my investigation of my central question I will also look at what has prevented the adoption of the minority body theory. The framing of disabled bodies as minority bodies has significance in all aspects of life and inherently requires an interdisciplinary approach of study. Program II allows me to take such an approach and to address my question from various angles and with different considerations.

This program will focus solely on physical disabilities. The term disability can be used to refer to any number of physical, emotional, cognitive, or developmental conditions. Aside from their categorization within society, there are not many significant and inherent commonalities between these types. The grouping together of all types of disability is even potentially damaging as it can lead to incorrect equations of one type with another. For example, the assumption that individuals in wheelchairs also must have cognitive impairments. Though I have chosen to focus on only one category of disability, I recognize that much of what I learn can be applied towards other types of disabilities. Also, I will be using the terms individuals with disabilities and disabled individuals interchangeably. I am aware of debates surrounding this terminology and have seen arguments for both sides. At this point, I do not feel ready to choose a side.

My program contains four modules, each of which corresponds to a learning objective. The modules are not distinct, though. Overlap exists between the modules and many of the core courses fit within multiple modules. For the purposes of a succinct program outline, I will

address each course as being within one module, but in practice this will not be the experience. There is no particular order within or between modules.

The first module, titled “Understanding Disability,” asks: what does it mean to be disabled? In order to justify the redefinition of disabled bodies as minority bodies I must first understand what disability is and how it effects an individual.

UNC’s English department has a course titled Intro to Disability Studies (Eng 270). Disability studies is a discipline that arose alongside the disability civil rights movement of the late twentieth century. It is an important and engaging field but has not received widespread recognition. Disability has a long history, one that goes back to the earliest peoples. Though it cannot all be covered in just one course, I will get an introduction to disability history. There are a number of philosophical arguments and theories that exist in disability studies. Some are specific to the field, such as critical disability theory, and some are theories that can be applied to the field, such as feminist theory. This course will introduce me to the most prominent theories in the field and will give me a base on which I can understand and apply these theories. I will be able to compare these theories to the minority body theory central to my program. Through discussion of disability history and theory the course will provide a general overview of what disability is and what it means to be disabled. There are many debates within the field of disability studies, the foremost of which surrounds what it means to be disabled and I see this course as my introduction to these debates.

“Nothing about us without us” is a slogan used within the disability community to address the necessity of inclusion of disabled voices in all aspects of disability policy, education, and representation. I believe it would be irresponsible and erroneous to study disability without including disabled voices. Since I am not disabled myself and I do not know of any courses taught by disabled individuals that discuss the disability experience and perspective I have chosen to design an independent study to address this. It will be done under the guidance of my advisor Dr. Diane Nelson and will be titled “Nothing About Us Without Us.” I will be reading works written by disabled individuals. Though the works have not been finalized, sample texts include: Disability Visibility, Being Heumann, Care Work: Dreaming Disability Justice, and Stairs and Whispers: D/deaf and Disabled Poets Write Back. These works tell about the unique lived experiences of individuals with disabilities in a way that studying the topic cannot. They delve into the emotional, the spiritual, the cultural, and the metaphysical. The purpose of this course is not to learn to better empathize. Rather, it is to view the disabled world from the perspective of its inhabitants. As I read I will maintain a journal to keep track of my thoughts. Dr. Nelson and I will discuss what I am reading and any relevant themes and questions that arise. Dr. Nelson has a background in recording the stories of marginalized individuals, namely those of the victims of the Guatemalan genocide. She has written extensively about the intersection of body politics and cultural rights, giving her a unique perspective for analyzing these narratives.

For this upcoming schoolyear I am on the Bass Connections team “Intersections of Race, Justice, and Disability in North Carolina” led by Dr. Michel Landry. Though it is a two semester (plus) project, I will be counting it as a core course only once. The project has three main objectives: (1) describe the lived experience of disabled members of the BIPOC community in North Carolina, (2) work to develop evidence based and more inclusive policy and practice response

mechanisms recommendations, (3) create a Massive Open Online Course (MOOC) to help raise awareness and build inclusion competencies among stakeholders. Much of the work for this project will be informed by interviews with individuals from across North Carolina. These interviews are another example of drawing knowledge about the disability experience from those with disabilities, the importance of which I outlined above. The overall theme of intersections for this program will also be part of my learning. Many disabled individuals live with other labels in addition to the one given to them for their disability. The interaction between these aspects of one's self is complex and nuanced. The other undergraduate students, graduate students, community team members, and faculty contributors will also be part of my learning. We will be working collaboratively, and I expect to learn from their experiences and perspectives.

The last course in this module is titled *The Self and Social Identities* (Psy 223). An individual's understanding of who they are is understood in relation to others. In this way the individuals around a person and the society they live in directly influence the person they become. In this course I will learn the mechanisms by which this occurs and how it influences individuals. I will also learn the other factors that are part of an individual's definition of self. The self is a complicated and multifaceted entity. This is true for all people, but for disabled people it can be particularly so. For disabled individuals their perception of self and their social identity are tied to their being disabled. To understand what it means to be disabled requires an understanding of self and personhood. Additionally, the social identity of a disabled individual is shaped by stigma. The world attempts to put disabled individuals into one category and this can conflict with who the individual desires to be and how they want to be seen. This can lead to vastly different understandings of the person and of the disability. This course will address the interplay between these aspects of personhood. Disabled individuals have more qualities than just being disabled so considering how these qualities interact to form self-image and a social identity is important and relevant to the meaning of disability. This course will also be helpful in considering the "individual with disability" vs "disabled individual" terminology debate.

The second module, "A Good Life" asks: what is a meaningful (disabled) life? Opposition to the minority body theory's claim that disability isn't inherently bad can be traced to differential understandings of meaning and purpose. In fact, disability is often considered a barrier to human flourishing. The courses in this module will help me address these issues of meaning in life.

I am currently taking *Death and Dying* (Soc 265) and will be including this in my program. Death is the antithesis of life. Therefore, in understanding death one can learn a lot about life. When an individual is nearing the end of their life, much reflection takes place both by the individual and those around them. This reflection is on the merits of the individual's life and the person whom they are. Understandings and reactions towards death reveal how life is valued. Obituaries, for example, demonstrate what aspects of a person's life are deemed important. Many individuals with disabilities have shortened life expectancies and the possibility of premature death can be realized at a young age. Shortened life expectancies are associated with differential perceptions of time. For these individuals a meaningful and purposeful life might differ from the traditional understanding. Additionally, there are people of the belief that living with disability is not "really living" and thus that a disabled life is not a good life. Discussion in this course of what is considered a tragic death is demonstrative of this view. These types of perspectives

substantiate how the quality of life with disability is related to understandings of meaning and purpose and highlight the importance of taking such a class.

Definitions and understandings of what a meaningful life looks like are highly reliant on the economic foundation of society. The course *Life Within Capitalism: A History of Its Values, Measures, and Struggles* (PolSci 252) addresses this reliance. Capitalism is prominent in society both in concept and in practice. Capitalistic ideas of production and accumulation heavily influence how people define success, meaning, purpose, and happiness. Since some disabled individuals cannot produce in the way prescribed within capitalism their lives are sometimes seen as less valuable. Learning about the foundations of capitalism and how they are applied in society will help me to better understand how disabled individuals are oppressed within capitalism. Another element of capitalism is the wage economy. This brings up the discussion of the care economy and the valuing of care work in society. Some individuals with disabilities require care taking which is often done by the family. Within capitalism this type of work is often not considered productive and is not highly valued. Thinking about why this is so and the effects of this will add to my knowledge of how culture, specifically capitalistic culture, drives definitions of meaningfulness and how this affects disabled individuals.

The course *Race, Genomics, and Society* (AAAS 251) will provide a different perspective in the discussion of worth and quality of life. A major aspect of genomics is the editing of genomes. Human genome editing has significant implications ethically, legally, and culturally. Genomic advancement offers new possibilities for pregestational diagnosis and gene therapy, ostensibly to *prevent* certain conditions that are considered disabilities such as Duchenne Muscular Dystrophy and some forms of deafness. Choosing to select against disability implies a life with disability is not even worth living. This relates back to the understanding of disability as being inherently bad and as potentially not being seen as purposeful. This course explores the impact of such technologies in relation to how we understand race, itself not a biological category but whose lived experience often has specific, constrained health outcomes. Though the course doesn't explicitly delve into disability, I will be able to learn about the implications of genomic technologies, health disparities, and values as they relate to race. Given my interest in thinking of the disabled body as a "minority body" this class sits at the intersection of understanding identity as the culmination of biological, cultural, and economic forces. As my career goal is to become a genetic counselor, I am particularly interested in this field. Despite quickly advancing genetic technologies there is not much focus in genomics on the ethical and practical implications of current and future perspectives on disability. What would it mean to counsel patients about health without conceptualizing disability in a negative light? What is the relationship between inclusion and equity that genetics can help patients navigate? This course helps me bring a different perspective of disability into the discussion, and I feel not only would it enrich my overall program's central idea, but it would also help me become a more responsive and informed patient advocate.

The third module is titled "Culture, Identity, and Inequality" and asks how culture, identity, and inequality interact to shape the experience of disability. This module independently investigates culture, identity, and inequality as well as the intersections between these three topics. All three relate to the concept of minority and to the redefinition of disabled bodies as minority bodies.

This semester I am taking Medical Anthropology (CulAnth 424) with my advisor Dr. Nelson and I plan to include it as a core course. One of the main themes in the course is the supposed mind body dichotomy and how this separation influences all aspects of health, well-being, medicine, and life. Belief in this dichotomy is not universal, and for many peoples it does not exist. This and related discussions of embodiment translate to differential understandings of disability and different perspectives on the role of disabled individuals in society. This course adds to the program by helping me to understand how important it is to consider culture when discussing disability. There is no absolute answer about for disability is, so it is necessary to see how it is represented and experienced in other cultures. Another theme of this class is making the familiar strange and the strange familiar. I can apply the same principles that we use to discuss cases in class to disability and the body. For many, disabled is strange and not disabled is familiar, but this doesn't need to be the case. This course helps me to understand that dichotomies do not need to exist and that there are multiple ways of understanding disability. One definition and one perspective of disability is not enough.

Within the Gender, Sexuality and Feminist Studies department I plan to take the course Interpreting Bodies: Identity and Beyond (GSF 363S). This course will help me to think about what it means to be in a body and how much the physical body actually determines identity. The body is a physical entity, one that can be viewed by others. But the body is also an aspect of the self. In this course I will look at the ways in which the physical body is understood and how it is used to define what it means to be human. Another thing that I will learn about within this course is the experience of individuals who do not live in a body that reflects how they feel and how they see themselves. This could be in relation to transgender individuals, but it also extends into disabled individuals. Individuals with certain bodies are more frequently subjected to oppression and inequality. In this course I will think about how the association between certain bodies and inequality influences the identity of the individual. The limits put on a person because of their physical appearance may not map onto the person's own vision of who they are and what they are capable of. The understanding and interpretation of embodiment is something that differs between cultures. I will consider cultural perspectives in how I attempt to view the body.

At UNC there is a course titled Race, Sexuality and Disability in the History of Western Christianity (Reli 368). Religion is an important aspect of culture that shapes how individuals view their world. For many individuals, religion shapes their identity and their understanding of their role in society. Additionally, religion, particularly Christianity in the United States, is ingrained in all layers of life—family, political, and social. For this reason, it is important for me to consider how religion plays into understandings of disability. Many individuals derive their understandings of meaning and life purpose from religion. Similarly, for many individuals, who they are, including the body they have, relates to their religion and their belief in a creator(s). In this course I will learn the nature of this relationship in the context of Christianity. Religion, religious texts, and religious leaders dictate what the ideal beings are and determine what is right and wrong. In Christianity disability is portrayed as a punishment for sinners in portions of the bible. I will learn the origins of this view and how it influences the opinions and actions of individuals. Religion is often used as justification for discrimination and inequality so this class will add to my understanding of why and how inequalities exist and are perpetuated.

The last course in this module is Social Inequality (Soc 211). Unequal opportunity is one way in which disabled individuals are distinguished from others. In learning about the nature and forms of social inequality and its basis I will be able to better understand how it effects individuals and groups of people. This class also looks at how institutions are involved in inequality and the existence of a culture of inequality. In order for understandings of disability to be reframed, institutions and individuals have to change, so it is important to look at what aspects of individuals and institutions are allowing for inequality. Discussion of the history of inequality and how it has changed over time will allow me to better understand the structures in which it exists as well as how positive change can be brought about. Disability rights addresses the inequalities faced and to fully grasp this I need to understand the basis of such inequalities. This class also addresses social inequality relating to aspects of identity such as age, race, class, and region. An individual with disabilities may also face inequalities relating to other aspects of their identity so learning how those characteristics may interact to further increase inequality is important to consider.

The last module is Representations of Disability which looks at the question of: How can disability be represented in a way that aligns with the “minority body” theory? There are many harmful representations of disability that don’t facilitate positive (or even neutral) understandings of disability. Redefining disability involves changing the narrative portrayed in media. Additionally, this module will be important to the development of my senior capstone project, both in regard to the project’s content and to making sure that the project appropriately depicts and represents disability.

Medicine and Documentary Photography (DocST 206S), the first course in this module, will allow me to explore the association between artistic representations of medicine and cultural understandings. Art such as documentary photography is done purposefully and conveys a message(s). If the photography is documenting an individual that person likely also has a vision of what is being depicted. At the same time, the person viewing the art comes with their own understanding of the world and this impacts what they take away from a piece. The various perspectives and intentions of these three parties doesn’t always align. With a polarizing topic such as medicine or disability these nuances are important to consider. In this course I will learn how to effectively get my message across. I will be able to analyze examples from established photographers as well as practice this skill by creating my own work. Through this practice I will improve my photography skills and receive valuable feedback from Dr. Moses and from my peers. This will be extremely helpful for my senior capstone project since I would like to include documentary photography in the project.

Field Work Methods: Cultural Analysis and Interpretation (CulAnth 302) will be in this module. The course will address best practices for researching and representing work related to a cultural group. In this course I will learn how to conduct research in the field, including learning how to observe and how to interview. These are skills that I will need for my capstone project since I plan to do a project that involves close interaction with both disabled and nondisabled individuals. The methods I learn in this class will help me to refine my capstone project so that I can conduct it most effectively. I will get practice observing and interviewing so that when I begin my capstone project I will feel comfortable conducting research on my own. Through this

course I will also learn how to accurately represent my research in ways that are consistent with the field of anthropology and with the minority body theory.

The core courses combined with the other courses I have taken so far at Duke and plan to take in the future will allow me to fulfill the breadth requirements outlined for all Duke students. I recognize that things are subject to change and I have a list of courses which I can take to replace courses that may not be offered when I can take them. I have included some of these courses at the bottom of my core course list. I have also noted a few courses which have not been offered in a number of years, but which if are offered again I would like to take. Additionally, if one of the core courses is not offered, I may choose to ask the professor who teaches it to allow me to take an independent study with them along the lines of the course. I would like to note that I have confirmed with the professors at UNC that their courses will be offered in the upcoming years. Also, because the UNC courses and the Bass Connections course couldn't be added to the long-range plan, my what if report includes filler courses which I won't be taking but which carry similar codes to the courses I actually plan to take. I believe that the core courses I have outlined will help me to investigate my overarching question and I am excited to be able to take each one.

Barnes, E. (2018). *The minority body: A theory of disability*. Oxford, United Kingdom: Oxford University Press.