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Title: Sticking up for them too: Understanding the university’s role in promoting advocacy among and for people with disabilities
Course: Anth411 Section 1G and 1U (Methods of Cultural Anthropology) Fall 2007 -- Nancy A Abelmann

About the Author: This set of data was collected and compiled by Jennifer L. Baldwin. This project stems from my interest in understanding and documenting the intersection of disability rights and people with disabilities everyday experiences. I am a second year graduate student in the MD-PhD program in cultural anthropology. My first exposure to disability studies came while taking a course on the History of Medicine with Dr. Daniel Wilson as a senior in college.

As a graduate student in medical anthropology and public health at the University of Pittsburgh, I decided to pursue graduate work on the experiences of individuals with disability while associated with the University, Community, Leaders, and Individuals with Disabilities (UCLID) program. I found the interdisciplinary approach to providing educational, medical, vocational, community, and social supports to people with disabilities exciting, as well as a model for how people with disabilities, public health, medicine and health sciences, social sciences, and community agents might serve to promote disability rights, citizenship and well-being for people with disabilities. As a fellow within the Maternal and Child Health Bureau’s Leadership Education Program in Neurodevelopmental Disabilities program, I completed ethnographic projects on South Asian NGO’s efforts at operationalizing disability rights discourse through programs and services for people with disabilities at local, community levels. This work culminated in a MA degree in Medical Anthropology and MPH degree in Behavioral and Community Health Sciences.

I came to the University of Illinois with knowledge of the leadership position that the university holds with regards to disability scholarship and education for students with disabilities. Given this reputation, I find the university to be a compelling site for exploring students with disabilities’ experiences both transitioning to college, as well as on campus and within the greater regional and national communities. I hope that this project may make a modest contribution to our understanding of the university’s role in the lives of people with disabilities, as well as documentation of student’s with disabilities experiences within institutions of higher education.

Keywords: Disability, people with disability, advocacy, student organizations, athletics

Abstract: This archived file includes the primary data and preliminary results of a semester long, ethnographic research project that sought to describe the experiences of students with disabilities at the University of Illinois.
I suggest that many of the student’s involved in this project came to the University of Illinois with a strong sense of self-advocacy and awareness of their identity as an individual with a disability. However, through their interactions with peers and participation in several university arenas, including classrooms, student organizations, wheelchair athletics, and residential living, these students developed a broader social network involving individuals with a diverse range of disabilities. Preliminary findings from this project suggest that these broader social interactions and networks among students with disabilities allow students to both understand the experiences of others, as well as to advocate for programs and policies that benefit both students and community members with disabilities. Thus, the university through it’s many features (just some of which include educational, extracurricular, leisure, social, and residential) provide settings and interactions through which a student with a disability can become engaged in advocacy behaviors for themselves and others, give primacy to their identity as a disabled individual, and perform a disabled subjectivity. However, while the university is a site for such opportunities, it is clear that there is more that can be done to foster student awareness, advocacy, and engagement particularly within and between students who are able-bodied and disabled. This project archive includes recommendations to the university based on these preliminary findings, as well as a proposal for a long term project to further examine the processes of empowerment in which students with disabilities engage, as well as the personal and institutional factors that impact student advocacy efforts and the outcome of these efforts.

**Initial Exercises:**

**The Terrains of Sidewalks and Fieldwork**

Fieldwork is presumed to require trust. But one can never know for certain that he or she has gained such trust, given the absence of any agreed upon indicator of what “full” trust would look like. …Surely it takes more than goodwill to transcend distrust that comes out of a complex history. Though participant observers often remark on the rapport they achieve and how they are seen by the people they write about, in the end it is best to be humble about such things, because one never really knows. -Mitchel Duneier, Introduction

*Do not open the door for anyone…* If I defied the maternal decree and opened this door, on what basis would I weigh Mitch’s intentions? How could I prevent him from appropriating me as mere data, from not giving me a voice in how the material in his book would be selected and depicted? How does a subject take part in an ethnographic study in which he has very little faith and survive as something more than a subject and less than an author? -Hakim, Afterword 321
Mitchell Duneier notes at the onset that he is “committed to the idea that the voices of the people on Sixth Avenue need to be heard” (13). To this end he is meticulous in his attentions paid to how these voices are heard and represented — details ranging from how and from whom the statements were garnered, to whether the statements were accurately recorded (and thus appear in quotation marks) or are recounted from memory or fieldnotes, to an explicit rejection of composite characters or events. Relatedly in the introduction from which the first quote was selected, he reflects a paragraph earlier that “like all observers, I have my subjectivities. I know that scrupulous adherence to rules of method will not lead necessarily to objective truth. I believe that what is most important is that I try to help the reader recognize the lens through which the reality is refracted” (14).

This notion that ethnographers possess a particular lens that shapes how the research is framed, conducted, and analyzed is a theme explored within Twine’s discussion within “Racial Ideologies and Racial Methodologies” about the impact that race plays within research. As one illustrative example, Twine discusses how a matched racial identity of a researcher with the participants assumes that similarities in racial identities leads to similarity in the lens interpreting the informant’s reality. However Twine notes that while racial insiderness may permit the researcher to gain a greater level of rapport and advance an antiracist political agenda that diversifies the academy, the matching of racial identity between researcher and informants does not necessarily create identical lenses. Twine herself notes this when commenting on the antiblack
sentiments of her Brazilian informants of African heritage and again in her critique that minority researchers are also at risk of using conventional social values and criteria within their evaluations of participants of the same ethnic or racial group. Duneier also implicitly comments on the dichotomous tensions that can erupt between the ethnographer and the subject when he states in his appendix on methods: “Here the researcher trades on the differences between what a subject thinks is significant to the sociologist and what in fact turns out, in fact from the dense stream of utterances and activity, to be of analytical use” (354). In this statement, he reveals the power and politics of his own book’s creation and construction. –Though he makes all of the attempts at accuracy and reflexivity throughout the book, it is still the social scientist acculturated to a particular set of professional values, techniques, and standards who deems noteworthy and worthy of analysis the material presented to him or her by the informant.

Though Duneier suggests that we be humble about the trust that we may or not have gained through our work, Hakim, Twine, and Stacey raise critical questions about what it is that informants should trust from the researcher. The ethical concerns about participants in fieldwork are similarly shared by Stacey and Twine within their respective discussions of feminist ethnographic projects and the role of race in social science research. Though I am not sure that I agree with the essentialist assumptions about women that Stacey uses to justify women anthropologists conducting ethnographic work on women’s worlds, I do appreciate her frank discussion of the difficulty such methodological approaches
that aim to closely explore relationships between individuals present for both the researcher and participants. (In many ways, I hope that this course can be a space for talking about how we as ethnographers and students actually navigate and cope with the conditions and situations that fieldwork places us in such as those discussed by Twine and Stacey) Perhaps beginning with Rabinow’s *Reflections on Fieldwork in Morocco* and Geertz’s response within “I-witnessing,” this notion of conducting symbolic violence against participants through one’s work has been written about, against, and out of extensively within postmodern and contemporary texts. Stacey’s article is an articulate and powerful reminder of the need for self-reflexivity and sensitivity that we must bring to each step of the research process.

Once again, we (not the least of which, as social scientists) are forced to contend with Duneier’s and Hakim’s probing questions into relationships between trust and power,

as well as the need to address Hakim’s inquiry on justifying the informant’s participation in

ethnographic work, and by extension the informant’s current position as something more than a subject but less than an author.

**Initial Exercises:** This exercise is not directly to the research project conducted and reported on this semester. However, it does direct attention to the use of space, people’s movements through it, and the way in which space can disclose contradictory messages for individuals with disabilities.

Admittedly, this project raised more questions than I was possibly able to answer or even explore within the single hour observation. Arriving into the “field” without an explicit agenda or set of questions or themes to explore left
me overwhelmed by the information and activities that were observable. After 10 minutes of capturing purely impressionistic and free flow information about the description of the place, bits of conversation, sensorial information, identities of the inhabitants, etc. I decided I needed to regroup and try to organize some of the initial information I had taken note of (and things of which I wanted to take note.) This space that I had chosen was a local coffee shop on a main street through campus that was heavily trafficked by both cars and pedestrians. My own familiarity with this space and others like it space set up certain preconceived expectations of what types of activities that I would observe, and the feeling that the place would present. From these initial impressions (both those taken from the first 10 minutes of observation and my own initial expectations), I (re) began my observations by denoting space in my notes for sensory information (smell, sights, tastes, touch, and sounds), and additional spaces for the people or occupants of the space, their conversations, the larger context in which this coffee shop is situated, the use of space and how people moved through it, and additional space for things that might present themselves in the next 50 minutes which I had not anticipated.

Several of these original categories were the vested interests that I brought to my observation that aligned with my own research interests. How do people embody a place? Or What are the sensorial impressions that are given by a place? How is space utilized? Does it preclude different types of bodies? How are class, identity, age, profession, and disability conveyed (or masked) by
Individuals? How do these factors shape interactions between people? How do individuals achieve particular goals of interactions? My notes from the observation include brief notes regarding many of these issues. For example, the place was notable for the strong smell of ground coffee that has a sweeter and stronger aroma than that of brewed coffee. Music played in a manner that was not quite background, but actually more prominent so as to mask many of the specifics of conversations between both staff and clientele and the groups of clientele arranged around the many tables. Frequently the sounds of the coffee grinder, espresso steamer, blender, and ice machine overshadowed the sound of the radio further masking any specific sound. Most of the surfaces of the establishment were smooth to the touch given the presence of polished wood and laminate surfaces. The walls are divided by a chair rail around the perimeter of the room that offsets the warm complementary paints of a bright yellow on top and a terra cotta red on the bottom.

Individuals by and large entered through a centrally placed door and crossed over to the service counter. This counter contained the cash register and was adjacent to the espresso machine allowing the staff the ability to take drink orders while simultaneously preparing an earlier order. Interestingly, people both employees and clients placed primacy on the interaction between the staff and customer. Conversations among groups of customers and the group of employees were both truncated when customers arrived at the counter. The counter was lower to the ground making it accessible to people in wheel
chairs. After receiving their drink, people frequently crossed back to a bar that contained containers of sugars, half and half, cup lids, and spoons and stirrers. This counter was placed much higher on the wall, thus requiring assistance for any one in a seated position. Additionally, the containers containing the cream were unmarked, requiring one foreign couple of women to ask a second male patron for assistance in identifying its contents. Individuals then moved back towards the door or towards the seating in the rear once they had finished preparing their beverage.

Besides these pre-conceived interests, I took interest in how people had arranged themselves within the coffee shop. Through attempts to both map out how individuals used the space as well as to catch the conversations in which people were engaged, a second set of novel questions emerged. The use of music within the coffee shop, as well as how people oriented themselves at tables and the tasks that people engaged in led me to questions about how both the coffee shop and its clientele employ space, sound, and activities to create a semi-private sphere within a public space. The end of my hour led me to note how people strategically spaced themselves around available tables, employed computer screens, ipods, and texts to isolate themselves (both individuals and groups of people) from others.

Initial Exercises: The findings reported from the textual analysis of the DRES website was not directly used within my research. However, it served as background information alerting me to some of the University’s...
missions and values regarding disability, as well as the discourse being used at the university.

My apologies to those of you who have to read this. This ended up being very long. (I really got excited about this analysis!) However, I have tried to include major questions in italics with my responses below. You might wish to read those sections that are under questions that appeal to you. Thanks! JB

The Organizational Culture of DRES

Much like my observations, I structured my analysis of the Disability Resources and Educational Services (DRES) document about itself (See “About DRES” at http://www.disability.uiuc.edu/page.php?id=12 ) by applying a set of exploratory questions that moved from more foundational intake material to broader conceptual ideas that marshaled the earlier foundational data to draw inferences about the experience of disability at UIUC. A summary of some of these findings are included below. (Where a particular observation lead to an additional research question that might require additional research and methods, I have also included these questions in parentheses to serve as a record of questions that I might wish to pursue later.)

Features and Production of the document:

Who is/are the intended audience(s) of this online document?

Though an explicit audience is not stated, we can infer that the primary audiences of this document are both the specific population explicitly mentioned in the document, “qualified students with disabilities,” as well as those groups which include “prospective students,” “current students,” “instructors,” and “staff” for whom specific hyperlinks exist within the larger University web design framework which lead individuals away from the “about DRES” document.

It is worthy to note the privileging of the individual as the primary social unit. There is not a link for parents and families, healthcare providers, secondary educators, or disability organizations that might emphasize a more interdependent social organization, as well as the other actors that might play a role in the student with disability’s life and experience at UIUC, or a faculty or staff member with disabilities experience.

What is the organization of the document?

The document’s content is organized by three key domains: Mission statement, Vision statement, and Objectives. These types of textual choices of how to describe and organize DRES’s identity reminds us that we are really looking at an organization and its culture. The use of the
Mission/Vision/Objectives trope fits a particular institutional imagining and structure of its purpose, goals, and actions.

This specific content is embedded in the larger UIUC website frame and design. Images and text on the periphery of the website, surrounding the text, provide hyperlinks to the UIUC homepage, DRES homepage, “UIUC Disability firsts” (which seems to be part of a larger narrative structure for the University of Illinois), “History of Disability Services at the University of Illinois,” and a sidebar menu including relevant contact information, and other domains within the DRES site. In contrast to a (narrow) sample of other UIUC department websites, the contact information for DRES includes a phone number that is followed by the abbreviation (V/TTY). This abbreviation is not defined for a popular audience, and therefore (might) reference a particular population that works with DRES. Specifically a hearing impaired audience and clientele are informed that they are able to use TTY services to send and receive typed phone messages to DRES.

What are the aesthetic(and thus program coding) features of the document? Do they present barriers in accessing information?

At first glance this document might seem fairly accessible to a range of individuals. The website is text heavy with images restricted to the borders. This allows someone using a text reader to take in the bulk of the information without visual image cues. The site also avoids a red-green color scheme, thus avoiding colors that color-blind individuals can’t adequately differentiate. However, on closer inspection several features do limit individuals with particular types of impairments. The images and hyperlinks scattered around the page do not provide alternative text that either describes the image and its relevance to the text or a description of where the hyperlink will take you. The document fails to provide an initial outline to the contents preventing non-visual users from creating a mental map of what type of information will be found below. It is not immediately clear that the color contrasts within the document would be able to seen by someone with low contrast resolution.

Not being a computer programmer, these were my rather novice impressions of the document. However a free online site (www.webxact.watchfire.com) provides analysis of any website regarding its accessibility, privacy, and quality. For Disability, it provides a detailed analysis of how the site conforms to a series of relevant, yet often taken for granted programming and aesthetic features that improve accessibility, as well as the rationale for using these features. This websites analysis found 38 inaccessible website features that fell within 6 different categories, some of which I highlighted above.

Who is the author or voice of this document?
There is no personal author of the website, again reemphasizing the primacy of organizational identity. The voicing of the document is impersonal and third person. Statements are bulleted and action oriented. There is no personal
testimonial on this page. Instead the collective DRES stands in for any particular individual.
(What is the rationale for producing this document?)

Textual Content analysis:

What terms are used to describe DRES’s target population? How is DRES’s target population conceptualized in this document?

Above, I already began to suggest that the individual is privileged over other social formations and units within DRES. Additionally, this population is identified as “people with disabilities” using People First language which highlights a particular historical and political moment in which DRES is operating. This identifier stems from a rejection of earlier prejudicial labels that emphasized the physical or mental difference, equating difference with deviance and one’s biology with one’s entire personhood.

Yet use of the phrase “qualified individuals with disabilities” also denotes a particular allegiance with particular power formations. A member of the UIUC community could not simply self-identify as a person with a disability and receive services from DRES. Rather, individuals who wish to utilize DRES as an organization must receive a “qualified” diagnosis from individuals operating within educational and biomedical systems. This use of the term “qualified” might also signify particular economic realities and the need to manage finite resources.

In ways aligned with both Fairclough’s discussion of assumptions and Strauss’s use of keywords in explicating cultural worlds, I have chosen to look at the use and/or repetition of particular words and how they provide insight into organizational values and notions of disability, and personhood, as well as how DRES is situated with regards to larger discourses and political formations.

What are the organizational values espoused by the document? (an incomplete summary)

[Q]ualified individuals with disabilities are afforded an equal opportunity to participate in and benefit from the curricular, co-curricular and vocational opportunities available at the University of Illinois at Urbana-Champaign through the collaborative promotion, provision and/or pursuit of innovative accommodative and educational services, and interdisciplinary disability research.

This Statement taken from the DRES mission statement highlights several organizational values which are summarized by the following key words: accommodation, research, equal opportunity, educational opportunity,
social opportunity, and vocational opportunity.

This emphasis on equality of opportunity is again reiterated in the envisioned environment that DRES aspires to create: DRES desires to create and promote an environment in which

the nature and degree of access to programs, services and facilities, and the level of self-determination afforded qualified persons with disabilities are indistinguishable from that which is available to their peers without disabilities (emphasis added).

From this statement a new key word is also identified: self-determination. From DRES’s focus within this statement, it is clear that DRES’s conceptualizations of “self-determination” and “equality of opportunity” apply mainly to the academic and built environment of the University of Illinois. (What is meant by “programs” in the above statement? What other environments are left out by this imagined environment – an environment of social and moral values? )

DRES also seeks to create an environment in which access will be provided by the university “as immediately and unobtrusively as possible.” Here, DRES is clearly defining itself as an extension of the university. This statement also elucidates that the key relationship for DRES is defined as that between the university and the individual with disability. DRES values (and also assumes that their target population values) efficiency, and limited intrusion into the lives of individuals with disabilities (maybe? This point isn’t clearly made.) (How and in what ways is access obtrusive? What are the consequences on the individual, the university as a bureaucratic institution, other members of the university community if access is obtrusive? What are the consequences of delimiting the relationship as that between the university and the individual in provision of services and access to services?)

What are the underlying concepts of disability and personhood? And What might be the origins of these concepts?

The concept of disability borrows from a social model of disability in which disability rests not in the individual but in the inaccessible environment and prejudicial attitudes. However, given the emphasis placed on “qualified disabilities,” DRES is also operating on a medical model of disability that underscores organic and physiological etiologies and processes that result in disability. While implied throughout the document, DRES’s notion of personhood recognizes “persons with disabilities…for their abilities, rather than their disabilities, or stereotypical attributes ascribed to their respective physical or mental impairments.” Again we see a notion of personhood that marshals both social and biological orientations to the body. They emphasize the socially
constructed meaning assigned to physical and mental impairments. (Impairments by World Health Organization definition emphasizes biological deficit or enhancement vs. disability’s meaning which emphasizes the interaction between the person’s biology and the environment.) This statement is also revealing in that rather than utilizing a holistic and integrated notion of personhood, DRES emphasizes strengths. Reiterating a focus not on stereotype (and thus on uniqueness) we see DRES once again capitulating an individualistic orientation to selfhood (as opposed to Veena Das’s notion of connected body-selves that do not privilege the individual as a key social unit, but instead extend personhood and the body to its interconnections with others).

**Future Research Questions:**
A) *Does the organizational ideology match the services provided?*
B) *What is this relationship between this document and wider public discourses about disability? This document never mentions ADA, but is marked by the same language as ADA and disability rights discourse.*
C) *The statement briefly references cultural inclusion with regards to research and advocacy. But this phrase is not elaborated upon. It does not seem to refer to inclusion of a disability culture, but rather people with disability accepted in wider notions of shared culture and a community at large. Are these two definitions of cultural inclusion opposed to each other or part of the same process? What would be the anticipated outcome on the part of DRES?*
D) *How do these values, services, and concepts of disability and personhood contribute to the experience of disability at the University of Illinois?*

**Initial Exercises:**

*Interview in fulfillment of 1st interview assignment: “How did you end up at the University?” and second Project interview. (If I have more time, I may try to add more analysis to this interview)*

Ted is a pseudonym for the interviewee. The interview was semi-structured and open ended in format. The basic interview schedule is provided below. Not all questions were asked. My exact wording of the questions is included below within the transcript.

1. How did you end up at the University of Illinois?

2. What is your year in school?

   Major?

3. What made you agree to participate in this interview?

4. What are the most significant influences that have shaped your experience at UIUC?

   You are a leader of a student organization – what made you decide to
be a member?

5. When you think of a veteran returning from the Iraq war, what do you imagine?

   Male vs. Female?
   Race or ethnicity?
   Age?
   Disability status?

6. Why did you think that you didn’t include characteristic X from your response?

7. What do you think influenced those perspectives?

   Media?
   U of I?
   Home?
   Personal friends?

8. Imagine this person enrolling at the University of Illinois. What do you think their experiences might be like?

9. What are potential resources for assisting them?

10. What are barriers?

11. What influences that picture that you see?

12. Is there a role that you think your student organization should play?

Any other departments or University affiliations?

Notes on Interview: The following interview was completed with Ted, a 21 year old male kinesiology major. He is a student with a physical disability who participates in wheelchair athletics both at UIUC and within national and international events. He is also a leader within a student organization on campus. Below is the transcript of a portion of the interview. Preliminary analysis and reflections are included at the end of this section.
In response to the prompt how did you end up at the university, Ted responded that he was originally from South Carolina,

T: “but when I was growing up, I started doing wheelchair sports when I was 12 or 13. For wheelchair track, there are three schools total with a wheelchair track team. This was the only one well run, as opposed to being…”

J: “Wow So because of your involvement in sports and the fact that the University of Illinois has a great wheelchair track.”

T: “There really isn’t anywhere else in the country that has that.”

J: “So that was pretty much the deciding factor for you.”

T: “Pretty much. I came here for track camp and like, sophomore year of highschool and I went home and was like Mom, if I get into that school I’m going I don’t care what you say about money. I’m going.”

J: “Haha. Cool. So once you got here, what has that been like? You know what, what has your experience at the University of Illinois been like both in terms of your participation in collegiate sports and you know you choose kinesiology as a major?”

T: “You know it really depends on the day. Like the track team is awesome. Like when we go on trips, everything is taken care. You know it’s just like any other varsity sport that’s going on here. But then like on campus here during the winter, we are Not treated so well, because we can’t get out of our apartment. So, I don’t know, it really just depends on where we are. A lot of the like Kines classes focus on like walking and stuff. And I’m like I don’t care. I’m just sitting here, and alright I have to analyze the way somebody walks. I’m not gonna have to do that ever, but sure why not.”

J: “So when you say “we” you have been kind of referencing that like “when we go on trips” “we” as athletes ? or…”

T: “Yeah, yeah”

J: “Ok, and especially wheelchair athletes?”

T: “Yeah usually The way I look at things is just like any other football or basketball players. We travel. We practice everyday just like they do. We practice on weekend unlike a lot of them. And uh it’s just… I know, I kind of get annoyed at the whole you know specify the wheelchair, and then they don’t know what to call the other one. So they call it like normal basketball”
J: “So how would you term the two groups.”

T: “We just call it either disabled or wheelchair and able-bodied”

J: “So that makes sense. It seems very logical. Um, you were talking about how you can’t get out of your apartment in the winter. Is that a different “we” than the “we” that you were talking about before?”

T: “We is just a general term for me and my friends in chairs.”

J: “I have a hard time getting out of my apartment in winter too easily, (laughing)”

T: “Yeah. Right. But I have a lot friends, and we missed a good three weeks of class last year because they didn’t clean up. We couldn’t get out of the apartment.”

J: “Who do you think was responsible for cleaning up?”

T: “The city on top of store owners. The entirety of Green St, I couldn’t push down the sidewalk. I live across the street from (...) and I couldn’t get there.”

J: “Yeah accessibility in what’s supposed to be a barrier-free environment is quite problematic. Interesting. So sports in a big part of your life here. Kinesiology is a frustrating part of your life. Why did you choose kinesiology?”

T: “Um, I want to coach wheelchair sports when I get out. Specifically kids. To me, I didn’t want to be just a administrative coach. I wanted to be the coach that knew what I was talking about and wether the kid is just starting out or whether they are elite level trying to make the Olympics, I can still help them. And that was the only way I saw to do that. was to know all of the science behind how things work and all that.”

J: “So besides kinesiology, what do you think have been formative experiences that you have had here? Or what do you think have been the most significant things that define your experience here?”

T: “Like in the disabled community here or at U of I in general?”

J: “Your call, you know the University of Illinois is a really broad and complex group of people.”

T: “I have to say my freshman year was the year the University of Illinois went to the finals in the NCAA . and everyone dashed to Green St after the final four game. And That was awesome. But it was kind of funny it was
packed, and I can’t see anything and there were two guys next to me, and they were like “Hey you wanna see …. I’m like ‘sure why not’. So they pick me up in my chair and hold me up over the crowd. So I got a look at it. But then the cops came over and freaked out because they had picked me up. And I’m like, ‘no, I told them to. Chill’.”

J: “So you think they were wrongly interpreting that as mayhem?”

T: “Exactly.”

T: “As for the disabled thing. I think my defining moments recently, I didn’t really have a lot of experience, before I got here, with disabled people outside of the wheelchair sports world. I know a lot of those, but I didn’t know very many deaf guys. I didn’t know very many guys with power chairs. But, since I’ve gotten here I’ve found like I can up with those guys and I can relate just as well as I do with wheelchair sports guys cause it’s all universal experience.”

J: “Interesting, so the two other communities that you references were “deaf guys” and “power chairs”? Is that what you said?”

T: “Yeah. On campus we have Beckwith Hall. I don’t know if you have heard of that. Its a dorm specifically for people who need more assistance, so if you need a personal assistant to get up and do your activities of daily living, you’d live at Beckwith. So we have a lot of guys in there that I have gotten to know through just …they use the same facilities we work out in for their physical therapy and everything else they do. So I’ve gotten to know a lot of them. And I just happen to be friends with some people in speech and hearing science who happen to be friends with some guys who are deaf. And it just went there.”

J: “So what has that been like? – moving from just a wheelchair sports community to a more.. It sounds like a more integrated community or broader definition of people with disabilities?”

T: “It’s actually been pretty cool. That’s the only way that I can think to describe it. You know I advocated for myself in middle school and High school. You know I stuck up for my view of things, but now I would feel justified sticking up for them too. Whereas before, I would have been like I don’t really get it so I can’t fight for them.”

J: “Interesting. So advocating for yourself for what you know to be your own issues, needs, and desires versus defending and working for somebody else’s which are probably different. Right?”
T: “Yeah, actually.”

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The remainder of the interview focuses on Ted’s perspectives on veterans and the resources at the university that might be useful in facilitating their inclusion within the university as well as their transition back to civilian life. Because these responses have now become less significant to my evolving research question and proposal, I have chosen to not include them in this document. If time permits later, I will add in these details.

**Preliminary Notes and Analysis:**
Ted is articulate about his changing sense of community in terms of students with disabilities. Wheelchair athletics exposed him to many other individuals with physical disabilities (most recently including disabled veterans having returned from the war and now being encouraged to participate in wheelchair athletic events). However, the range of individuals with disabilities was limited to relatively “abled” athletes. It is interesting that Ted’s expanded community and interactions with students with diverse types of disabilities has lead to a sense of being able to advocate across different disability categories. Ted also speaks with a consciousness about disability politics and advocacy. His frustration with being unable to get out of his house is framed as an issue of accessibility. Similarly, his commentary on the lack of awareness of individuals entering the rehabilitation profession is rooted not so much as a lack of insight into “proper etiquette” for working with people with disabilities, but rather as a lack awareness of the actual experiences of people with disability and their interactions with individuals who are unconsciously patronizing.

**Question:** Revised Question (11/07)

How does the university, as a site of student engagement in educational, social, residential, and occupational activities influence students with disabilities’ advocacy behaviors and contribute to these student’s enactments of a disabled subjectivity?

Old Question (10/2/07)

In addressing the US House of Representatives on January 22, 1907 on behalf of disabled veterans who had fought in the Civil and Mexican-American Wars, Robert Burns Brown, Esq, himself a disabled veteran, makes an eloquent appeal for pensions not simply based on the needs and impairments of these veterans but also as entitlements for the moral and social worthiness of these men and their past military service to the country. Eleven years later in the wake of World War 1, the Smith-Sears Act of 1918 was signed into legislation which established and subsidized state vocational training programs for disabled veterans, marking one of the first public policies on disability of the twentieth century (Scotch 381). In a similar vein of self-
advocacy as Brown’s addressal of the US Congress, a group of World War II veterans with disabilities traveled to the University of Illinois to protest the closing of a regional rehabilitation hospital that was under the University’s administration (UIUC’s DRES website). Gaining fuel from the GI bill and public discourse on vocational rehabilitation and entitlements for veterans with and without disabilities returning from the war, this small group successfully petitioned for the creation of educational services and access to the University through the creation of an on-campus, experimental rehabilitation program. Since this early history, the university has claimed several foundational achievements in areas of disability sports, access, and educational support services for people with disabilities. From this history that is both national and local in its scope, the dialogic relationship between the experiences of veterans with disability and contemporaneous social views and public policy on disability gains saliency. With recent media and social attentions being paid to the experience of disability among returning veterans from the Iraq war, one can question what the current role of the University is or should be given it’s past and present leadership on disability. Similarly, this question could be broached, in part, by exploring what the current relationship is between the university and disabled veterans in the Champaign area and on the University Campus. Also informing this question is that of how UIUC’s past leadership in disability policy, veteran services, and education impacts the experience of students with and without disabilities currently.

**Plan:** Revised Plan 11/07:  
Please see final discussion for a detailed discussion of both my revised research question and research methods.

***

Old Plan 10/2/07

**Research Participants:**

Individuals would be purposively sampled from the following organizations (to be elaborated upon throughout the semester):

- Administration and Staff of UIUC’s Disability Resource and Disability Research Institute

- Student organizations for people with disabilities such as Sigma

- A local community based meeting group for veterans with disabilities

- Given the prominence of ROTC programs for the branches of the armed forces, individuals from these organizations will also be included.

**Methods:**
Archival research on documents about the university’s changing mission, policies and services for students with disabilities. I will examine documents on material that discusses the experiences of students with disabilities at the university. One example is a publication entitled “Sigma Signs” that was published by the earliest students with disabilities on the UIUC campus.

Participant observation within community based organizations serving veterans with disabilities and people with disability (both formal organizations as well as social and self-help groups). This work might explore how the university figures or does not figure into the daily experiences, discourse, and social imaginings of individuals associated with these programs. Similarly, participant observation among other campus organizations, both institutional and student organized.

Interviews of individuals from the above organizations and affiliations will be selected for interviews that explore their relationship with the university, their experience within the community and university, and views regarding the relationship between the university and veterans with disabilities. Questions for an interview script will be informed by preliminary analysis of fieldnotes taken from participant observation sessions. A subsample of interviewed individuals will be selected for participation of more in-depth semi-structured life histories. The purpose of these life-histories will be to further document individual’s experiences, values, and imagined possibilities for the university.

Additional research methodologies such as community visioning and community asset mapping from public health and community health methodologies will be used within this project in order to accomplish a understanding of the communities involved in this project. Asset mapping is tool of community development and assessment that brings communit members and leaders together to identify and document the capacities and asset of a community that can be mobilized to address a particular issue (Gilmore and Campbell 2005, Hodges and Videto 2005). These assets can be materic resources and facilities such as hospitals and businesses, as well as mor abstract and ideological items such as shared identity and empowere populations. Community Visioning is a second methodology that will be employed within this project in order to document community perspectives of current and future conceptualizations of disabilities, disability rights, an individuals with disabilities. The purposes of community visioning is to develop a shared vision of what the community members would like their community to become, to help people to think creatively and move beyond discussions of immediate problems, and to find common ground between conflicting interest (Novak 1990, 1996; see also Hancock 1992 ). General practices of community visioning involve bringing community leaders and members together to participate in a guided imagery exercise, and to then engage in a group discussion of how their community would look under a given condition (i.e. fully inclusive and equitable community for individuals with disabilities or particular relationship between the university and disabled veterans).
Data: The purpose of this preliminary interview (to explore why someone made the decision to come to the University of Illinois) was combined with my first project interview. Please see the entry under "Preliminary Interview" for a discussion of this interview.

The Archive: This discussion of the material available within the Student Life Archives was useful in conveying to me the important role that wheelchair athletics has played in the university’s historic and current practices for individuals with disability.

The Archives provided me with a rich and diverse set of resources for exploring my topic. Searching for such terms as “disability,” brought me to archives that covered approximately 50 years of UIUC administrative documents from the Board of Trustees, publications on physical disability and mental health from the law school, University policies on retirement benefits and accident insurance. Though the law school might serve as an interesting site for exploring the role of the university on disability policy, I desired to find more documents pertaining to the university culture regarding disability and the experiences of students with disabilities over the years. Therefore, I searched alternative terms such as “Delta Sigma Omicron”, and “wheelchair”. These terms resulted in some of the same university administrative documents, but also brought up information specifically relating to the College of Applied Health Sciences, as well as the Division of Rehabilitation Education Services. Even without locating the specific and archives themselves, I was able to access the mission statement for the newly renamed College of Applied Health Sciences. The College states that its mission is "to advance research, instruction and public engagement that promotes the development of healthy, livable communities, facilitates optimal living with disability and promotes health and wellness across the lifespan and throughout a diverse society.”

Given this emphasis on disability, it is clear that the College of Applied Health Sciences may be an important site that influences its students’ perspectives of disability and the culture on campus.

The archives that most interested me were those found by searching under the term “wheelchair.” I realized the importance of this term from my research in the IDEALS database, as well as my interview with a student in Delta Sigma Omicron. Prior to these experiences, I would have thought that the term “wheelchair” was too narrow for my interests. However, given the important historical and contemporary roles that wheelchair athletics have played in the recruitment of students with disabilities and promotion of disability services, the term “wheelchair” serves as an important referent for disability culture on campus. This term lead me to the DRES scrapbooks kept between 1947 and 1986. The brief description notes that these archives contain information on “Scrapbooks, including newspaper clippings and photographs of the Rehabilitation Education Center, wheelchair sports, Gizz kids basketball tournaments and trips, Director Timothy Nugent; Delta Sigma..."
Omicron awards (1959-60, 1965-66, 1970-71), World Wheelchair Games (1982-84), and related activities’ (Student Life Archives). It was also extremely helpful that a more detailed description of the contents had been produced (similar to the summaries of the contents of the letters that we examined at the Student Life Archives). This list contained important information about news clippings, individuals considered to be key figures within this particular DRES collection, and personal records kept by DRES. The titles of the news articles suggest important events in UIUC’s disability history in which wheelchair athletes traveled to Africa, Europe, and Tokyo for both competition and service, a military officer’s injuries were profiled in a local paper, individuals were honored for their service for children and adults with disabilities, and key actions promoting universal access were documented. Although these documents are mediated through journalistic frameworks, my hunch is that reading through these documents will provide me with both a better sense of what the University saw as key people and moments in its disability history, as well as a view of how disability was framed and spoken about in local and national spheres. Though incomplete and impersonal, these documents provide a sense of the culture in which disability was lived and experienced by UIUC’s past students.

Archive Information: Division of Rehabilitation Education Services Scrapbooks, 1947-86  Record Series Number: 16/6/12 Volume: 3.5 cu. ft.

Link to the PDF on DRES scrapbooks: http://web.library.uiuc.edu/ahx/uasfa/1606012.pdf

Data:  Time Allocation Study

Data Continued  November 5th, 2008 (with email follow-up/ responses provided November 11th, 2008)

Research Questions:
What are the important life domains of a student with a disability’s life that impact his or her experience at and engagement with the university?

Background:
Time allocation methodologies seemed like appropriate means for accessing information that would answer the research question that had evolved from the previous participant observation exercise with DSO. However, the methods as cited within Gross were altered for the purpose of this exercise. Rather than employing direct observation of an individual, spot-checks, or employing a self-diary of activities, the information presented below was constructed from a 1 hour interview in which an extended discussion about a typical day for the student with a severe physical disability was discussed, taped, and transcribed. This method thus makes the information biased and partial. It reflects the self-reported activities of this student, but does not comment on actual activities.
observed by the researcher. This information is also limited to the current schedule of this student, and is thus not a mean average of activities over several days, weeks, or even months. With these limitations stipulated, I do believe that perceptions and representations of where and in what activities one spends their day can be informative to a research project if even biased by the interviewee’s subjectivity. Additionally, I would argue that this adapted time allocation strategy is a reliable medium for soliciting fairly accurate information about the activities of a student with a severe physical disability. Frequently, this individuals follow a highly structured and well defined schedule in order to balance vocational/educational, personal, medical, and social needs. Also these individuals frequently need to inform other individuals of their routine and needed accommodations. Therefore, individuals with physical disabilities might be described as having a heightened awareness of their activities of daily living and the time expenditures required for each. I would also add that this format for collecting information is far briefer and less invasive than the activities described in Gross. Thus it reduces the risk of exhausting individuals with physical or cognitive disabilities for whom extended talking, concentration, or physical activity can be taxing. In this case, Freddy describes talking and group meetings as exertions that leave him exhausted at the end of the day because of the muscle exertion it takes for him to speak clearly and loud enough to be heard.

The information that is presented below is extracted from a larger interview that is not described here due to time constraints. Where clarifying, I have added additional information from earlier portions of the interview. Freddy choose his pseudonym for the purposes of this interview.

**Time Allocation:**
This activity was completed within a larger interview with Freddy, a nineteen year old Sophomore who identifies himself as “severely physically disabled.” Freddy is majoring in Administration under LAS with the desire to be a hospital administrator. Freddy is highly involved in many university councils, organizations, and activities. (I choose to not describe them here for confidentiality purposes.) In response to my question “Why did you decide to participate in this interview?” Freddy responded “to promote awareness.” From this response it is clear that I am as much a medium for disseminating Freddy’s message, as Freddy is a medium for my own research objectives. With this openness in intentions, a dual obligation opens up for the researcher. Freddy had certain objectives for this encounter. He expected me to be a conduit for his message which had it’s own agenda. The desire of how Freddy wished to portray himself and the message that he wanted to promote may not necessarily have conformed to my own goals of the interview and the information that I would extrapolate from it. Through all levels of his participation at the University of Illinois, Freddy wanted his life to be an example of what students with disabilities could accomplish. He wanted to demonstrate that a student with a severe disability could accomplish the same
things as those who were able-bodied.
As we began to discuss where he spent his time, I decided that a time allocation revealing where the bulk of his activities were spent
What follows below is the transcript from these activities.
Freddy decided to discuss “a typical day on his most busy day of the week”, Wednesday. This in itself was a decision that I didn’t challenge. Choosing his busiest day was certainly not exemplar of all of his experiences, nor would this discussion give me an idea of how he balanced personal, social, and academic demands and desires over the course of a week, month, or academic year. (Ultimately, I think that a longer term project involving discussions and observations of an entire semester would be necessary to give a better picture of his life at UIUC.) However, as the session progressed, it was possible for me to identify common elements that were illustrative of his life at UIUC. For one thing, Freddy’s life is highly structured given his care-giving and life needs. While there is some variability in his routine schedule (and these were in fact activities, such as his what and when he ate, with which Freddy experimented upon coming to campus), Freddy maintains a regimen that is consistent across most days with variable changes for class schedules and meetings.
Freddy wakes up at 7AM to a personal attendant (PA) who physically gets him out of bed, manages his shower, and dresses him. (“The need to find, hire, and train which is a whole different story in itself.” It seems that Freddy has gone through a few different PAs in a search for someone compatible with him and his needs.) Freddy is probably quite aware and used to talking about his schedule given the fact that he must inform and train others to be able to accomplish his personal and academic needs)

F: “They wake me up, and they shower me, and they get me ready, and stuff like that. You know shower, dress, everything… literally everything.”

J: [if you feel comfortable, what do you mean when you say everything?]

F: “sure, they lift me, they change me, they wash me, they dress me, they put me in the chair. And I’m very, very picky. I always joke that it’s not easy to look this good. It’s not literally because it’s a lot of work. Because when I have to tell you to move my shirt again and again and again, You’d be like “what are you talking about?” because it’s no big deal to you. But when I have to sit all day, it’s different and so… I’m very picky. All of my PAs will tell you that I get on their last nerves. I’m done with that at 8:30, and then I usually have class from 9 to one.”

He gets to class by taking a bus for people with disabilities or using his private driver which he pays. He finds that “especially in the winter time when the weather turns, [he] needs to pay a driver because the bus only runs every other hour.” But he has classes back to back, and therefore needs to pay a driver to
be able to attend his classes.

He has classes in different buildings. One is in the Armory, and the next is in the Engineering MSEB on the Engineering quad. Because of the distance, he requires a driver to transport him between the two locations.

F: “I can’t walk from the armory to MSEB in ten minutes, so I have a driver take me. I mean every class, its basically the same routine. I have somebody open the door for me. I have somebody move the chair for me. I have my laptop with me, and I see what happens.

He has an especially light laptop (2 lbs) with a ten hour battery that he keeps out and on his lap at all times. Freddy notes that

“his laptop is very important to him as it has everything on it. And that’s really all I use. That’s one benefit of college. There isn’t really a lot of different things that happen. You can pretty much predict what things are going to happen in a lecture hall. Which I like. I like lecture because I know I don’t have to worry about ‘oh, is there going to be a group project today, and do I have to have my notes or my book?’ You usually just sit there, and I take notes on my laptop. I don’t use a notetaker. I usually am able to keep up pretty well. You know, I am really a big fan of planning ahead. At the beginning of the semester, I ask very in-depth questions of the professors about the format of everything. And they have to tell me because of ADA.”

At 1 PM, Freddy goes home for the afternoon. His PA prepares his meals, as well as his nightly medications and feeding tube. From 1-2:30, Freddy uses this time to eat lunch, refresh, and go the bathroom. Freddy explained that it takes him about an hour to eat because he eats really slow due to muscle weakness. To supplement the small quantities of food he eats at lunch and dinner, he receives extra nutrients and calories through a feeding tube overnight. (This accounts for why he doesn’t eat breakfast.)

Freddy was willing to discuss the more intimate details of his activities of daily living. He explained that the presence of a PA was required for him to toilet. He explained that he is conscious of his liquid intake because he doesn’t have either the time or personal attendants to help with his toileting needs during the day when he is away from home. He also contrasted his toileting needs versus a woman’s, and found the fact that he could use a urinal far more convenient and less intrusive than a females’ toileting needs. (He did note that his PAs have raised concerns about his kidney health because of his strategy to avoid fluid intake and having to toilet during the day.)

From 2:30 to 4:30, Freddy uses this time for phoning friends or colleagues regarding his many associations with university organizations and clubs. He also uses this time to email individuals related to his many leadership
positions on campus, or he completes homework activities.

At 5:00, a driver transports him back to campus for his meetings. As I alluded to in his introduction, Freddy holds several prominent leadership positions and associations on campus. He sees this as a significant part of how he serves as a rolemodel for people with disabilities. He also believes that these positions allow him to raise awareness about disability needs and the abilities of people with disabilities.

From 5:10 – 10:30 PM, he stays in the student union where he meets with several committee chairs (usually in 15 minute intervals) These meetings with committee chairs keep him informed of activities with regards to the committees that he leads and needs to report on within a larger student organization. At the completion of these meetings, he has a general meeting that he attends from 8:30 to 9:30.

When asked what he does between 9:30 and 10:30 when his driver picks him up, Freddy responded that he usually uses this time to wrap up several hours of work, and to have some time to himself.

“I do a lot of speaking which can be exhausting because you know I can’t speak very loud, and it’s hard to talk a lot, especially when doing it for so many hours. At 9:30, I usually like to have an hour to myself to kind of recap and send emails and stuff. Sometimes I have to meet with other people for other stuff.”

He found that these types of activities could be exhausting both because of the considerable amount of talking that he had to do, as well as the duration and intensity of his scheduled meetings.

F: “At 10:30, my driver picks me up and I go home and eat dinner at 10:30. So it’s late. Then I eat dinner from 10:30 to 11:30, and then I go right to bed. And the night routine takes about half an hour – 45 minutes. You now just changing, get put in bed, get hooked up to my machines, that’s my routine.”

F: “I sleep from 12:30 until 9 AM. But sometimes I only get 7 hours of sleep. …The hardest part is going form 3:30 to 10:30 without a break. That’s really difficult for me.”

J: “What do you do for entertainment?”

F: “To be honest, when I have a break I like to just do nothing. I love to watch TV. But I mean, I would choose to see a movie over going to a bar. You know, I mean, I do both but some days you just don’t have the energy. … You’ve got to remember that all that time [at meetings], I didn’t do any work. So sometimes, I don’t go to bed because I have to do homework. When I
assess my life, I do it through three things. My immediate needs, my academic needs, and my personal needs.”

J: “So I noted that you said that you have these three things that you assess your life with: immediate, academic, and personal. Can you give me kind of a percentage that you think your time is committed to academic stuff vs. personal. Like if you had a pie chart, which portion would be academic, which portion would be personal, and which would be immediate?”

F: “Umm, that’s a tough question. I’d say immediate like 10% because I never…” (Bad researcher, I cut him off at an interesting point.)

J: “Can you give me some examples of immediate?”

F: “like eating food, huh huh, like if I were to stop talking to you and think ‘ok, what do I have to do immediately,’ I would say right now, I need to eat before I go to bed and send two emails. Those are two things I need to do today, because if I don’t do them everything will be a catastrophe. Those are my immediate needs. And then academic needs, is like ‘oh, I have a paper to write that I didn’t finish.’ That’s academic. And then personal ‘oh, I have to go to rehearsal tomorrow night from 8-10. I have to go to the board meeting on Wednesday, I have to do this on Thursday.’ So I’d say that personal things take up the largest chunk.

J: “So Pie charts, is, you have 90% of that pie chart left…”

F: “I’d say 50 for personal, and 40% for academic.”

At this point the interview had to end because Freddy’s driver had arrived to pick him up. He has to schedule these activities in advance.

Addendum:

The following questions were requested by me through email. Freddy’s responses follow.

J: a) In terms of course readings, what format do you use to both access the readings and complete them? for example, do you purchase and read physical copies of the book, electronic versions of the book, audio versions, etc.

J: b) Are there particular challenges that emerge every semester for you with regards to classroom design, teaching format, or course assignments, or even something else?

J: c) impressionistically and in contrast to other environments that you have been in, do you think that the university as an institution is a difficult place to be when you have a physical disability? Why or Why not?
J: d) any additional thoughts that you would like to add or share at the 
moment? (I hope that we will have more opportunities to talk in the future, but 
I thought I would give you an opportunity to contribute any additional 
thoughts that may have come to mind after the 
interview.)

F: a. I use text conversion from the testing center. My books are scanned and 
made into pdf format. That way in class, I always have any book, as long as I 
have my laptop.

F: b. Being an old university, I may not always get to sit where I want in a 
classroom because of a step. Actually, I find college easier in terms of in class 
exercises because teachers tend to just lecture. With my current setup, 
lecturing works just fine for me. Also, note taking is sometimes a struggle. I 
can write, but not very fast. So any supplemental material a prof can offer me 
is always helpful.

F: c. I believe that any institution is going to be harder to navigate with a 
physical disability. In grade school, the learning environment was more 
compact and inclusive throughout. Here, each building has its own set of 
issues, so an accommodation that worked for one building may not work for 
another. Also, since I utilize campus for my entertainment/social life, it can be 
an issue to fit it. Most people at universities are 20 somethings that walk, so an 
on campus business would appeal solely to that age group. In the outside 
world, a business must appeal to a wider and more diverse market, so chances 
are that something like a bar in a city is always going to be more accessible 
than one on a college campus.

**Preliminary Analysis:**

Supplemental methodologies - As suggested, I feel that this exercise would be 
most relevant when contextualized within a larger time frame, when compared 
against other students experiences, as well as actual observations of Freddy’s 
daily activities. Going through the paces of his day would be a valuable and 
informative exercise for the researcher because such an activity would draw 
attention to the taken-for-granted nature of so many embodied activities and 
processes of daily living.

Freddy insightfully imposed a categorization of his daily activities when he 
classified his life as having immediate, academic, and personal. One analysis 
might be to use these categories to compare his impressions of his time use to 
the activities that he reports for his Wednesday schedule. Additionally, we 
might choose to classify his activities using other categorizations such as 
relevant life domains such as education, social, advocacy, kinship, religious, 
transportation, etc. From this preliminary list we begin to organize Freddy’s 
life activities in a new way. For example, he spends about 3.5 hours on
personal care needs per day which include eating, bathing, dressing, etc. He also spends about 50 minutes engaged in activities related to transporting him to, around, and from campus. His academic time on Wednesday’s takes up 4hrs of his day, while extracurricular activities consume 4.5-5.5 hours per day. He engages in rest or leisure activities for about 2 hours on Wednesdays. Far more nebulous and difficult to classify from this preliminary description are those activities that might be classified as “advocacy” and “social”. In order to proceed in classifying these types of terms, I would first prefer to have a discussion about what activities he might classify under these two terms. Additionally, these types of terms and associated activities lend themselves to overlap with activities categorized under different headings.

Freddy is conscious of his class positioning that permits him the ability to hire personal attendants and private drivers. (commentary not transcribed) This intersection between class positioning, independence, and advocacy would be an interesting theme to pursue within the population of students with disabilities at the university.

An additional domain that I would like to pursue is the relationship between independence (that Freddy referenced in other parts of the interview) with his dependence on others for his personal care, access to and within classrooms, and university accommodations. (I am beginning to realize that I need to flesh out more of those dimensions of the interview.) I do not wish to challenge Freddy’s description of himself as independent. However, I wish to highlight how this complicated relationship between independence, that might better be labeled as self-advocacy, and support systems that facilitate Freddy’s access to the university and social mobility is negotiated by students in constructing their identities and relationship with the University. In general, I am interested in these tensions between discourses privileging independence versus behaviors and institutions (formal and informal) that lend themselves to more interdependent systems and interactions.

Revised Research Question:

There are quite a few new directions embedded in the above discussion.

What do students with disabilities define as the relevant life domains within the University environment?

What factors influence student’s participation in and activities associated with these various life domains?

How does class positioning, influence these domains and mobility within and between them?

Something about advocacy, independence, and support systems???
In this exercise, I will first lay out what the argument or thesis of the film would be. I will then proceed to describe a storyboard layout (suggested within the linked website for the course assignments) that would be used to script, film, and convey the argument of a 2-3 minute film. Raw film footage would be obtained by following three featured individuals around over the course of their daily activities. Student’s would not be asked to enact a particular event, but rather to move us through their day. My hope that such filming comes closer to representing the actual student’s experiences on campus as opposed to a recreated simulation of their days. Particular attention would be paid to filming students engaged in the activities that I think provide mechanisms for advocacy behaviors to emerge: wheelchair athletics, extracurricular student organizations, class room settings, vocational programs, and residential living. Additionally, student’s interactions with individuals and the built environment would be emphasized.

In her article “Seeing the Disabled: Visual Rhetorics of Disability in Popular Photgraphy” Rosemarie Garland Thomson writes about the effect various photographic techniques including camera angles, individual’s poses and actions, and the type of disability represented have on the representation and meaning assigned to disability for main stream audiences (2001). Mindful of Thomson’s discussion, efforts will be made to include the desires of individuals in representing themselves and their lives, as well as particular filming styles that avoid representations that appear demeaning or exaggerations of the student’s experiences on campus. Images and representations of disability would be carefully chosen in consultation with not only the film participants, but also the DSO members who participated in the ethnographic portion of this project. Camera angles and foci when fixed on the student with a disability would be straight on, from the level of the film participant. This is to avoid camera angles and framing techniques that seek to patronize, exoticize, or elevate to subject to a super-heroic status. Student’s will be encouraged to get behind the lens to film both their visual and ideological perspectives of the subject matter. Attempts would be made to capture close up images of the participants that may or may not include key markers of a disabled status, such as a wheelchair, as well as images of individuals with disabilities using the particular technologies and apparatuses that help them complete their daily activities. The tone of the film would decidedly not be one of heroic feats or super-human attempts to overcome one’s disability. In many ways, I would want all material included in the film to “normalize” disability and make us familiar with the image of disability, while not seeking to make this film a statement that these students experiences are like every others’. This will inevitably be a fine balance to achieve.

Images and situations involving advocacy behaviors would be edited to select for the most illustrative examples. Students would then be interviewed on film to discuss their involvement in the example and how they perceive themselves as advocating for themselves or others within it.
Synopsis: This film short will depict the university’s position on disability policy and services for students with disabilities. The film will then move to show how students at the university utilize these resources and create new opportunities for themselves and others through their own engagement in university life. The film concludes with areas that present the most challenges for student’s engagement and advocacy.

I. Opening scene (30 secs)
Image: formal image of the University (perhaps an image of Follinger and the quad)
Sounds: Students’ quotes read by student participants:
A) “You know I advocated for myself in middle school and High school. You know I stuck up for my view of things, but now I would feel justified sticking up for them too. Whereas before, I would have been like I don’t really get it so I can’t fight for [people with different disabilities than my own].”
B) Quotation on Freddy’s decision to participate in this interview and other campus activities to promote awareness

II. Title (5 seconds)
[Image: title slide] “Sticking up for them too”

III. The University and Disability (45 seconds)
[Narrator is a UIUC student with a disability who states:]
“The Disability resource and education Services at the University of Illinois at Urbana Champaign states within its mission that:
‘qualified individuals with disabilities are afforded an equal opportunity to participate in and benefit from the curricular, co-curricular and vocational opportunities available at the University of Illinois at Urbana-Champaign through the collaborative promotion, provision and/or pursuit of innovative accommodative and educational services, and interdisciplinary disability research’.”

[Image of this quote will appear on screen superimposed over image of university from opening clip]
[Image] Montage of DRES and university resources: ramps, student using text reader technology, DRES building, Beckwith Hall, wheelchair sports facilities, etc

IV. Students with disabilities’ engagement with the university (90 seconds)
[Narrator continues] However, the university is a place where student with disabilities do not simply participate and benefit from the university’s resources. They are involved in creating and broadening the opportunities available for themselves, other students and community members.
A) Wheelchair athletics
[Image of students playing wheelchair athletics]
[commentary] wheelchair athlete is interviewed about the role of wheelchair athletics in student’s lives.
B) Student Organizations
[Image with commentary] DSO meeting student talking about activities of DSO and student’s participation in the student organization

V. Barriers for student engagement (90 seconds)
[Narrator states:] “Despite student engagement that promotes greater student involvement and the university’s stated mission to provide opportunities for students with disabilities, there continues to be barriers that prevent student engagement.

[Image of wheelchair accessible entrances removed from main entrances (which students state disrupt socializing and interactions), snow covered sidewalks, inaccessible classrooms and campus bars.]

[Narrator] “There are still greater opportunities to promote student advocacy and knowledge about the experiences of students with disabilities.”

[Researcher interview question:] “Have you heard about the history of culture of people with disabilities:”

[Image:] montage of student responses (both with and without disabilities)

Coda:
This film seems very Brechtian – overly expository and didactic in its message. Alas, I am no Bertolt Brecht and this is not likely to be destined for any legendary status. For me, this exercise highlighted just how text centric my academic training has been. It was far easier for me to think about the narration for such a film, as opposed to the actual visual and auditory elements that truly depict the thesis of the film. I also find it interesting, that I felt kind of creatively paralyzed, and kept feeling that I wasn’t very good at this. It is probably not all that different from how I felt when first trying my hand at academic writing. I think we as scholars and practitioners need more rehearsed practice at honing this type of scholarship.

Discuss: Sticking up for them too:
Understanding the university’s role in promoting advocacy among and for people with disabilities

Introduction
The shifting nature of this study from a project about student’s perceptions of veterans with disabilities and the University’s response to one that focused upon the experiences of students with disabilities at the University of Illinois permits a range of preliminary conclusions to be drawn regarding student’s experiences and the opportunities that the university presents for expanding notions of community and advocacy on the behalf of a diverse group of people with disabilities. I suggest that many of the student’s involved in this project came to the University of Illinois with a strong sense of self-advocacy and awareness of their identity as an individual with a disability. However, through their interactions with peers, participation in educational involvement in extracurricular organizations and sports, and independent living these students developed a broader social network involving individuals with a diverse range of disabilities. Often coming from high schools in which they were the only student with a disability, the university provides several opportunities for students to both understand the experiences of others, as well as to advocate for programs and policies that benefit both student and
community members with disabilities. However, while the university is a site for such opportunities, it is clear that there is more that can be done to foster student awareness, advocacy, and engagement particularly within and between students who are able-bodied and disabled.

Research Question

How does the university, as a site of student engagement in educational, social, residential, and occupational activities influence students with disabilities’ advocacy behaviors and contribute to these student’s enactments of a disabled subjectivity?

Methods

In accordance with the course design and requirements of Anthropology 411, Research Methods of Cultural Anthropology, several ethnographic and qualitative methods were employed in this project. A semi-structured, open-ended interview was completed with Ted, a 21 year old male with a physical disability who was involved in wheelchair athletics and majoring in Kinesiology. This interview was designed to elicit information regarding why the student choose to attend the University of Illinois; the student participant’s involvement in campus activities such as coursework, student organizations, and student athletics; as well as his reflections on what he felt to be the defining experiences of his time at the University. Though not transcribed, this interview also explored the student’s perspectives of veterans returning from the Iraq war in partial fulfillment of the original research question. By design, this interview was exploratory in nature and served as an introductory exercise in understanding some aspects of the community that I would continue to work with in this project.

Participant observation of a meeting of a student organization for promoting disability rights provided information about issues of relevance to the lives of student’s with disabilities, as well as activities of leisure, employment, academic, and outreach activities in which students were involved. Attention was paid to the researcher’s own subjective embodiment and emotional state during this meeting in a way that employs Sara Ahmed’s conceptualization of affective economies (2004). (Please see moodle exercise under fieldnotes for greater detail.)

Finally, a time allocation study that was modified from Gross’ articulation of this methodology explored a student’s perceptions of the activities that structure his day at the University of Illinois. This study was completed with 19-year-old Freddy, who is a sophomore administration major who self-identifies as severely physically disabled. Rather than employing direct observation of an individual, spot-checks, or employing a self-diary of activities, the information presented below was constructed from a 1 hour interview in which an extended discussion about a typical day for the student with a severe physical disability was discussed, taped, and transcribed. This modification is thus limited in that it reflects self-reported activities of this
student, but does not comment on actual activities observed by the researcher. This information is also limited by its restriction to the current schedule of this student, and is thus not a mean average of activities over several days, weeks, or even months.

With these limitations stipulated, I argue that the perceptions and representations of where and in what activities one spends their day can be informative to a research project if even biased by the interviewee’s subjectivity. Additionally, I suggest that this adapted time allocation strategy is a reliable medium for soliciting fairly accurate information about the activities of a student with a severe physical disability. (Please see Moodle Time Allocation exercise for lengthier discussion.)

Analysis of information collected from these methods was conducted primarily through triangulation of fieldnotes, interview transcripts, peer and faculty feedback, as well as discussions with research participants. Triangulation of this information occurred as it was collected, as well as at the conclusion of this preliminary project. What follows are preliminary conclusions regarding the university’s role in facilitating student advocacy behaviors and performance of disabled subjectivities.

**Preliminary Findings**

**Advocacy behaviors**

From analysis of these methods, I suggest that the university facilitates advocacy behaviors through several key mechanisms. These include, but may not be limited to, A) the opportunity for students with disabilities to expand their peer networks to include individuals with a diverse range of disability types, B) the necessity for students to negotiate diverse physical and epistemological classroom settings and curriculum requirements, C) student engagement in extracurricular athletics and student organizations, and D) students’ experiences living independently on or off campus. As I don’t yet have enough information regarding the role of independent living on advocacy behaviors, I will restrict my discussion to the first three mechanisms for the purpose of this paper.

**Expanded Peer Networks**

Both students who provided interviews for this project stated that they were the only student with a disability in their school. While Ted had interactions with other individuals in wheelchairs through his involvement in wheelchair athletics, he notes that he had limited interactions with other individuals with different types of disabilities. He states:

“As for the disabled thing. I think my defining moments recently, I
didn’t really have a lot of experience, before I got here, with disabled people outside of the wheelchair sports world. I know a lot of those, but I didn’t know very many deaf guys. I didn’t know very many guys with power chairs. But, since I’ve gotten here I’ve found like I can hang out with those guys and I can relate just as well as I do with wheelchair sports guys cause it’s all universal experience.”

Beyond finding that he can relate to individuals with other types of disabilities due to common experiences, Ted notes that an increased ability and confidence in advocating for a broader community of people with disabilities has been fostered through such interactions. The following discussion illustrates this point.

Ted: “On campus we have Beckwith Hall. I don’t know if you have heard of that. Its a dorm specifically for people who need more assistance, so if you need a personal assistant to get up and do your activities of daily living, you’d live at Beckwith. So we have a lot of guys in there that I have gotten to know through just …they use the same facilities we work out in for their physical therapy and everything else they do. So I’ve gotten to know a lot of them. And I just happen to be friends with some people in speech and hearing science who happen to be friends with some guys who are deaf. And it just went there.”

Interviewer/Jenn: “So what has that been like? – moving from just a wheelchair sports community to a more.. It sounds like a more integrated community or broader definition of people with disabilities?”

Ted: “It’s actually been pretty cool. That’s the only way that I can think to describe it. You know I advocated for myself in middle school and High school. You know I stuck up for my view of things, but now I would feel justified sticking up for them too. Whereas before, I would have been like I don’t really get it so I can’t fight for them.”

Ted is articulate about his changing sense of community in terms of students with disabilities. Wheelchair athletics exposed him to many other individuals with physical disabilities. However, the range of individuals with disabilities was limited to relatively “abled” athletes. Ted’s expanded community and interactions with students with diverse types of disabilities has also lead to a sense of being able to advocate across different disability categories.

Negotiating Educational settings

Though not always exhibited as advocacy behaviors, students with disabilities at the university develop a sense of awareness about the experiences and needs of individuals with disabilities through their negotiation of diverse curriculum,
teaching styles, and classroom settings. For some students, attending classes involves a basic routine of identifying individuals who can help them to access the classroom and material being taught within it.

Freddy notes:

I mean every class, it’s basically the same routine. I have somebody open the door for me. I have somebody move the chair for me. I have my laptop with me, and I see what happens. You can pretty much predict what things are going to happen in a lecture hall. Which I like. I like lecture because I know I don’t have to worry about ‘oh, is there going to be a group project today, and do I have to have my notes or my book?’ You usually just sit there, and I take notes on my laptop. I don’t use a notetaker. I usually am able to keep up pretty well.

Students with disabilities demonstrate an awareness that peers, faculty, and legislation facilitate their ability to succeed in the classroom. Freddy continues:

You know, I am really a big fan of planning ahead. At the beginning of the semester, I ask very in-depth questions of the professors about the format of everything. And they have to tell me because of ADA.

However one’s access and success within the classroom is limited by both one’s own physical abilities as well as architectural and urban designs. Freddy highlights both points below:

Being an old university, I may not always get to sit where I want in a classroom because of a step. Actually, I find college easier in terms of in class exercises because teachers tend to just lecture. With my current setup, lecturing works just fine for me. Also, note taking is sometimes a struggle. I can write, but not very fast. So any supplemental material a prof can offer me is always helpful.

Ted also notes how the curriculum within the courses is sometimes not mindful of a diverse range of physical bodies, abilities, and behaviors. He observes that within his kinesiology major:

A lot of the like Kines classes focus on like walking and stuff. And I’m like I don’t care. I’m just sitting here, and alright I have to analyze the way somebody walks. I’m not gonna have to do that ever, but sure why not.”

Though not explicit, Ted seems to have identified certain assumptions that normalize and essentialize human bodies and experiences that may be a work
within the curriculum.

Ted similarly expressed dismay that many of his able-bodied peers majoring in rehabilitation programs lacked an awareness not of the rights of or proper etiquette for working with people with disabilities, but instead of the actual experiences of people with disabilities and patronizing and pejorative social responses towards disability.

**Extracurricular activities promoting awareness and advocacy for people with disabilities**

This project identified three key types of extracurricular activities through which students with disabilities gain greater awareness of disability issues, and are given opportunities to engage in projects that benefit students and community members with disabilities as well as contribute to positive representation of people with disabilities. These three extracurricular activities include athletics, employment, and student organizations.

**Athletics**

Wheelchair athletics has played a prominent role in the history of the university since its first students with disabilities enrolled at the university (See discussion in archives activity). Therefore one would expect involvement in athletics to be a large part of student life for some students with disabilities. However, the success of the University of Illinois wheelchair athletes at collegiate, national and international sporting venues highlights the dual role that athletics plays for some students with disabilities at the university. UIUC’s wheelchair athletes promote high levels of athletic achievement, while simultaneously promoting a positive image about what individuals with disabilities can achieve. Ted states,

“Like the track team is awesome. Like when we go on trips, everything is taken care. You know it’s just like any other varsity sport that’s going on here. The way I look at things is just like any other football or basketball players. We travel. We practice everyday just like they do. We practice on weekends unlike a lot of them. And uh it’s just… I don’t know, I kind of get annoyed at the whole you know specify the wheelchair, and then they don’t know what to call the other one. So they call it like normal basketball”

In this statement, Ted notes that his participation in athletics is an opportunity of equality to be treated like many of the university’s other elite able-bodied athletes. However, it has also not escaped his attention that more needs to be done to increase awareness among the general public about wheelchair athletics.
Occupational

Students with disabilities involved in campus employment, such as the student at the student organization meeting who presented on his work at the University Text Conversion office, also engage in activities that develop awareness of the diverse needs of students with disabilities. The student employee highlighted the several different types of formats that traditional text books had to be converted into in order to make them accessible to individuals with very different types of disabilities. Additionally, this student’s participation drew his attention to the current limitations in text conversion processes, noting that in particular the technology did not exist to reliably convert foreign language and equation-based texts into alternative non-print formats.

Student Organizations

In response to my question “Why did you decide to participate in this interview?” Freddy responded “to promote awareness.” Freddy is reflective on the role that his involvement in student organizations plays in promoting awareness of disability issues and modeling the contributions of people with disabilities. Through all levels of his participation at the University of Illinois, Freddy wanted his life to be an example of “what students with disabilities could accomplish.” He wanted to demonstrate that “a student with a severe disability could accomplish the same things as those who were able-bodied.” His extensive involvement in such activities as demonstrated by the time allocation study reveals the primacy that such activities of activism and advocacy have in his experience at the university.

Similarly, students involved with the student organization observed in this project were engaged in activities that promoted awareness of the experience of disability, as well as advocated for changes at the university that would benefit people with disability. Such examples of this included petitioning the university to modify the wheelchair seating area of Assembly Hall in order to allow students in wheelchairs to see performers on stage. Students within this organization also were involved in outreach activities with the community in which they promoted awareness about disability services the university, as well as engaged in charitable activities for children with disabilities in the community.

Disabled subjectivities:

Rather than being foundational to a student’s formation of an identity as a student with a disability, I would argue that the university augments this identity process by providing opportunities for students to act as a “student with a disability.” As I have stated earlier, many of the students with whom I spoke chose this university for the resources and opportunities that it afforded to them as students with disabilities. Additionally, many of these students, acknowledge previous occasions when they had to advocate for themselves in high school settings. This is illustrated most clearly by the young woman who filed a law suit against her high school under ADA. Yet the university through
it’s many features (just some of which include educational, extracurricular, leisure, social, and residential) provide settings and interactions through which a student with a disability gives primacy to their identity as a disabled individual and performs a disabled subjectivity. Certainly, the advocacy behaviors discussed above are one such way through which students construct and perform a disabled identity. I suggest that the motivations for such performances are born out of necessity to perform a label that has been attached to them most of their lives, but also through a willingness and desire to re-appropriate such a label and offer up new meanings of what it means to be disabled for both other individuals with disabilities and a great public consciousness of disability issues.

However, while highlighting the opportunities that the university experience presents for students with disabilities, several limitations and areas of improvement have also been up-rooted. Far more research must be conducted to support many of the preliminary claims made above. One such next phase of research might look at the university policies and services that define much of a student with disability’s experience at UIUC. Additionally, an exploration of the barriers that the university presents to students’ engagement in advocacy behaviors would certainly balance the more celebratory tone of the university’s role in student’s lives that this discussion has thus far presented. Additionally, there are several recommendations that can be made to the university at this time in order to better foster and improve student advocacy, awareness and engagement in disability issues. (Please see Moodle exercise for such a discussion.)

**Research Proposal:**

You alternatively can open the attached document "Research Proposal." (I recommend this strategy, as the original formatting is preserved within the word document format, as opposed to the changes made to the document when converting to HTML.)

**Beyond Access: Understanding Students with Disabilities’ Advocacy Behaviors and Roles within the University**

When disabled people enter higher education they are taking up an opportunity to increase their knowledge, to debate their social skills, to obtain good qualifications and to expose themselves to debate and discussion. It is an important experience for empowerment (Hurst, 1996, p. 141)

Starting from Hurst’s assertion that experiences with higher education lead to empowerment for students with disabilities, this project seeks to move our knowledge beyond well-documented descriptions of the limitations and barriers that students with disabilities encounter within institutions of higher education. This project seeks to look at processes of empowerment in which students with disabilities engage, as well as the personal and institutional factors that impact student advocacy efforts and the outcome of these efforts. Such an analysis is necessary if we are to better understand student’s with
disabilities experiences within institutions of higher education, as well as develop university policies and practices that foster student empowerment, self-determination, intellectual development, and civic engagement. This project seeks to address these dimensions of students with disabilities experiences by addressing three interrelated questions: A) How does the university, as a site of student engagement in educational, social, residential, and occupational activities influence students with disabilities’ advocacy behaviors and contribute to these student’s enactments of a disabled subjectivity? B) What are the mechanisms through which students with disabilities make claims to material resources, rights, and/or citizenship within various sociopolitical domains relevant to their experiences at the university? C) Of what consequence are the social, cultural, and economic positioning of a student with disability in determining how and to whom the student makes these claims and the outcome of such attempts?

Table 1. Research Goals and Objectives proposes four research goals and related objectives that will provide the relevant information necessary to answer the above questions.

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<th>Research Goals</th>
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<td>1. To critically assess how students with disabilities understand and define (and redefine) their roles within the university inclusive of such domains as education, extracurricular, family, social, health, work, and civic.</td>
<td>1a. To describe the various domains in the student with disability’s life that are relevant to their experiences within higher education.</td>
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<td>b. To document the student’s classification of roles prior to college and new roles within the university; and</td>
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<td>c. To describe the process of negotiating and/or forging new relationships with peers, faculty, service providers, family members, and community members.</td>
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<td>2. To examine the nature of agency and advocacy among students with disabilities as it relates to relevant social domains in the student’s life.</td>
<td>2a. To provide a definition of agency from the perspective of students with disabilities;</td>
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<td></td>
<td>b. To provide a definition of advocacy from the perspective of students with disabilities; and</td>
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<td>c. To describe the student’s process of advocacy and the domains in which it occurs.</td>
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<td>3. To describe how university philosophies, policies, and practices regarding disability are understood and</td>
<td>3a. To document the university’s perceptions of disability, disability rights, and life goals for individuals with disabilities; and</td>
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embodied or actively contested by students with disabilities within their everyday practices.

**b.** To examine how university policies regarding students with disabilities are negotiated by these students by examining where student discourse and behaviors parallel and challenge university philosophies, policies, and disability programming objectives.

| 4. To examine how different social, cultural, and economic factors affects a student with disabilities experiences within the university. |
| 4. To describe the experiences, advocacy behaviors, and outcomes of advocacy for students with disabilities representing different gender, class, racial and ethnic identity, and disabilities. |

**Project’s Relevance to Existing Literature:**

Physical and cognitive disabilities have been viewed as a marker of disease (ICD-10), of physical deficiencies, malformations, and malfunctions (WHO 2002), of abductions of (Das and Addlakha 2001, Hyland 2000) or simply alterations to (Ingstad 1995, Seymour 1998) kinship expectations and domestic duties, of circumscribed economic and productive roles (Stiker 1999, Foucault 1973), or of social and wider community obligations (Hyland 2000, Barnes, Mercer, and Shakespeare 1999, Shakespeare and Watson 1997, Ingstad 1995, Goffman 1963). These indices indicate that disability is not simply located in the physical body; it is also a socially and culturally constructed identity (Longmore and Umansky 2001; see also Shakespeare and Watson, 1997). In the tradition of many others (Goffman 1963, Foucault 1973, Turner 2001, Weiss 1994, Kohrman 2005), I argue that disability and bodily alterity constitute a site upon which power, biomedical knowledge, social meaning, and embodied experience intersect, and where identities are constituted and enacted.

Though institutions of higher education have recognized the biomedical and social nature of disability through their provision of academic accommodations and modifications to the built environment, few studies have examined the role of universities in students with disabilities’ enactment of disabled identities. Much of the literature regarding students with disabilities’ experiences in institutions of higher education focus on students’ difficulties in accessing information about enrolling in higher education (Madriaga 2007), tensions inherent in teaching and assessment modalities (Fuller, Bradley, and Healey 2004), and dimensions of university policy and practices that work against or contribute to student marginalization and discriminatory practices (Holloway 2001; Shevlin, Kenney, and McNeela 2004). These studies tend to fix attention on the piecemeal efforts of university’s to provide disability services, equitable treatment, and access to students with disabilities. Much of this literature highlights the problem of services that are individualized as opposed to institutional responses that place the burden on students to disclose their disability status (and negotiate people’s...
responses that are sometimes doubtful or cynical), search out services, inform faculty and staff, and arrange the provision of services. While such studies contribute important insights into areas where university and national policies can strive to improve the treatment of students with disabilities and ensure equal access, these studies fail to provide much data on how students navigate, manage, and behave within such environments. The current literature fails to specify and contextualize university policy and philosophies regarding disability, and instead paints a picture of university disability attitudes, policies, and practices in broad, generic terms of inclusive discourse, but inaccessible environments. Further, these studies border on framing students as victims of such inaccessible systems and environments, while failing to describe the agency and meanings assigned to such enactments of disabled subjectivities on the part of students with disabilities within institutions of higher education.

While several studies include the voices and perspectives of students with disabilities at institutions of higher education, (Holloway 2001; Low 1996; Shevlin, Kenney and McNeela 2004; Madriaga 2007; Fuller, Bradley, and Healey 2004; Boxall, Carson, and Docherty 2004), student’s voices tend to be limited to discussions of the challenges they face and the exclusive practices of the university that makes higher education inaccessible. These studies fail to examine how student’s with disabilities engagement with higher education can be, in the words of Hurst, experiences for empowerment. Yet, preliminary data obtained from a pilot study to this project suggests that students with disabilities are actively engaged in advocacy behaviors for themselves and others through their participation in several university arenas, including classrooms, student organizations, wheelchair athletics, and residential living arrangements. The university through it’s many features (just some of which include educational, extracurricular, leisure, social, and residential) provide settings and interactions through which a student with a disability gives primacy to their identity as a disabled individual and performs a disabled subjectivity.

Jacqueline Low has written about student’s negotiation of disabled and non-disabled identities among students with disabilities (1996). She cites the motivations and environments within the university setting that require and allow students with disabilities to put forth, mask, and negotiate their identification with a disabled status. While others have discussed student’s decisions to disclose or not disclose a disabled status, this study is novel in that it emphasizes that one’s disability status is actually lived as a process and is something that must be and can be managed by the student. Low highlights that the negotiation of both a disabled and non-disabled identity by students is inherently contradictory: the need to acquire assistance and modifications requires disclosure of a disabled identity in order to attempt to pass as non-disabled in educational settings. Additionally, individualized tactics such as self-deprecating humor and distancing from other students with disabilities that are employed to minimize the differences between those with and without disabilities has little likelihood of transforming the notions of disability as deviant and different.

Building upon Low’s work and the limitations within our current understanding about students experiences previously described, this study will address the student with disabilities’ identity as a process requiring management and
particular enactments within the university environment. Specifically, this study will examine student’s enactments of a disabled subjectivity through advocacy behaviors and student engagement with the university to overcome limitations within multiple domains of university life. Further, this project aims to problematize our conceptualizations of both students with disabilities and university policies by an explicit focus on the behaviors, interactions, and outcomes of students from a diverse range of class, gender, racial or ethnic, and disability categories as they engage with specific university environments and policies.

Research Design
The site of this 2 year project is the University of Illinois at Urbana-Champaign (UIUC). Historically, the university has promoted itself as a leader in research, education, and services for students with disabilities. This location is my academic home, giving me continuous access and familiarity with several dimensions of university life and institutional culture. This familiarity can be fraught with problems including the potential to overlook key issues and dimensions of the university that an outsider would observe. However, I argue that this “native” stance within the university is advantageous in that it permits a close intimacy with the practices and philosophies of the university (which are arguably contested by many of the diverse factions of the university community) through daily immersion in the university culture, as well as a sustained commitment to this project and the communities it seeks to represent. Further, the University of Illinois is a compelling site for this study given its ability to serve as a cross-cultural counterpoint to the studies in the UK and Canada with different, though overlapping histories and legislative policies regarding disability and disability rights.

I will serve as the principle investigator on this project. However, this project will also recruit and collaborate with 3-4 undergraduate and graduate students with disabilities in completing this research project. Data collection and analysis will be divided among collaborators based upon each’s familiarity and experience in using the techniques. One aim of this project is to mentor and instruct undergraduate collaborators in ethnographic research relevant to their own interests within this project and experiences with disability. All data collection and analysis will be overseen by myself.

Recruitment and Sampling Methodology
Students will be primarily recruited and enrolled in this study through the Disability Resources and Education Services (DRES) at UIUC. In accordance with UIUC’s Institutional Review Board policies and approval, letters and emails (available in multiple text conversion modalities) describing the goals of this study and what participation entails for this study will be sent to all students registered with DRES inviting interested students to contact a specific DRES officer about participating in this study. DRES will then communicate the names and contact information of these students to me. I will then contact students, make the final selection of research participants, and ensure their confidentiality in this project. DRES is viewed as a necessary broker in student recruitment to ensure non-coercion of participants on the part of myself as the primary
researcher, as well as to ensure access to resources that may be necessary to facilitate research participant’s full participation in this study. 
Research participants will be recruited and selected from the following groups: college aged students with disabilities (inclusive of mobility, vision, hearing, learning, and mild cognitive impairments impacting physiological or social functioning) aged 18 years to 28 years currently associated with the University of Illinois at Urbana-Champaign; DRES staff; coaches of wheelchair athletic programs; faculty with whom students with disabilities are enrolled; academic advisors; and department heads from the basic sciences, social sciences and humanities, applied health sciences, and business and administration programs. Using a preliminary intake form upon contacting interested students, I will construct a sample population (n=30) employing a stratified, purposive sampling technique in which students will be selected to represent a diverse range of disability types, majors (or anticipated majors), ages, genders, racial or ethnic identity, class, and extracurricular involvement (Bernard 2002). Similarly, purposive sampling methods will be used to recruit DRES staff, faculty, wheelchair athletics coaches, academic advisors, and department heads. Whenever possible, these participants who represent the university’s staff and administrative framework will be selected for their association with a student with disability enrolled in the project. The one exception to this applies to the sampling of university department heads whose input will be used, in part, to frame the university philosophies and practices regarding students with disabilities. Therefore, these individuals will be purposively selected for their association with students with disabilities enrolled in their departments or to represent a range of department responses to disability across different subjects and epistemological approaches to knowledge and learning. This use of purposive sampling strategies in this project embraces Becker’s discussion of sampling techniques that balance the desire to represent the whole, with the need to construct a sample that addresses the research questions under consideration and to search out the examples that will challenge and “upset” our thinking (1998). In this case, I have eschewed the idea of representing the whole of the university through random sampling in favor of focusing specifically on student’s with disabilities and those associated with their experiences at the university. Given the observation that student with disabilities are under-represented in institutions of higher education (Low 1996), this seems like a necessary compromise in order to adequately represent the experiences of students with disabilities.

**Methods for collecting data**

Below follows a description of the methods that will be used in collecting information relevant to research questions goals and objectives. The specific objectives that will be addressed by each method are identified by their number within Table 1, and are included in italicized parentheses within the discussion of the particular method.

**Phase 1. Archival research and primary document collection and analysis (Objectives 3a and 3b)** will be the primary focus of the first three months of this project, but will also continue through the duration of the project. The Student Life and Culture Archives housed at the University of Illinois will be
the primary source of archival research relating to materials about disability programming, education, and students experiences within the last 40 years of university history. Of particular interest are the newly available archives on DRES. Additionally, university publications both those explicitly and not explicitly relating to disability issues on campus will be collected, scanned into a permanent electronic record, and analyzed for the messages they reveal about university philosophies, practices, and policies on disability. These materials might include university recruitment materials, yearbooks, course catalogs, newsletters, websites, university and department mission statements, and DRES publications.

Phase II. Interviews and participant observation will commence during the fourth month of this project, and continue throughout the 24 months. Open-ended, semi-structured interviews will be conducted with: A) university staff, administrators, and faculty (n= 20-25) as identified within the section on participant recruitment. These 1 hour interviews will focus on the individuals views on disability, disability rights, and the life goals of students with disabilities, as well as their practices within the administrative office, academic department, or classroom with regards to disability and students with disabilities (Objectives 2c, 3a, and 3b). B) Student participants (n = 30) will participate in a series of three 1-hour interviews. The first interview in the series will ask students to discuss their perceptions of their roles within the university and under what conditions or in what spaces they perform these roles (Objectives 1a, 1b, 1c). The second interview will ask students about their definitions of agency and advocacy, as well as what factors promote or hinder their ability to advocate for themselves or others (Objectives 2a, 2b, 2c). The third interview will document student with disabilities’ perceptions of university philosophies and values regarding disability, disability rights, and their life goals. These interviews will also ask students to reflect on how these values mirror or diverge from their own beliefs and values about these topics (Objectives 3a and 3b). Finally students will be asked to provide examples of how they think their gender, class, racial and ethnic identity, and disability status influences their experiences at the university and their advocacy and engagement with the university (Objective 4).

Participant observation (Objectives, 1c, 2c, 3a, 3b) will commence along with the interviews in the 4th month of this project and will continue for the duration of the study. Participant observation will examine how students negotiate their roles within various domains of the university such as classrooms, extracurricular events, social spaces, and residential living spaces. These observations will also examine students’ advocacy behaviors and the outcomes of these efforts within these domains.

Phase III. Beginning in the second academic year of this project, a subset of students interviewed (n = 10) will be selected for further participation in the collection of life histories and time allocation analyses. In her discussion of the use of life histories with individuals pursuing adult education programs including people with disabilities, Julia Preece notes the utility of life histories in understanding current values within the context of one’s past experiences (1996). Further, this methodology, though highly interpretive demonstrates how individuals position themselves in relation to the social contexts of their lives.
Within this study, life histories will be used to explore students with disabilities' understandings of their past and current roles (Objective 1b), the meaning that they give to their advocacy and engagement with the university (Objective 2c, 3a, 3b), as well as their perceptions of how particular dimensions of their identity have informed and continue to inform their experiences at the university (Objective 4).

Additionally, a modified version of Gross's (1984) description of time allocation studies will be conducted to document the roles, activities, and management strategies that students engage in throughout their days and over the course of an academic year (Objectives 1a, 2a, 2c). Students will be asked to discuss the details of their day in an interview format, as well as permit a researcher to follow them throughout their daily activities several times during the academic year. Preliminary findings from a pilot study for this project documented how such analyses can be useful in examining how students with disabilities manage their own personal, academic, and social needs throughout the day. Such management strategies are part of the agency that students exhibit within the university environment.

Phase IV. In the final 4 months of this project, all research participants will be invited to participate in an assets mapping project (Gilmore and Campbell 2005, Hodges and Videto 2005) and community visioning exercise (Novak 1990, 1996; see also Hancock 1992). These events will be forums for the researchers to share their preliminary insights drawn from the project, solicit feedback about these preliminary findings, and to begin to identify the desires and aspirations of what they would like the university to become for students with disabilities, as well as the material and ideological resources available for achieving such a community. Both the identified resources and community vision would be incorporated into the findings and discussion of this research project, as well as recommendations made to the university.

Analysis

Qualitative, ethnographic analysis will be applied to data obtained from the above methods.

Information provided from primary documents, archival documents, and staff interviews all contribute to what Ewell describes as the university’s mythology and reality regarding disability (1998). Such information, in combination with student with disabilities’ experiences and perspectives aim to highlight the discrepancies that may exist between University’s image of itself and its actual practices and policies. This nuanced discussion university philosophies and practices permits for comparison between how these policies and practices are embodied and negotiated by students with disabilities within different contexts within the university.

As discussed by Strauss, textual analysis of transcripts from student interviews and life histories will be assessed to identify key words, contiguity, voicing, and self-image in order to construct personal semantic networks constructed from the participants experiences and employed in negotiating and assigning meaning to their engagement with the university (Strauss). Relatedly, Strauss’s textual analysis methodology will be employed in order to delineate ways in which student’s experiences and views on disability issues align and diverge with
university policy. Student interviews regarding university disability policies will be assessed for points of emotional and motivational hot spots, ambivalence, integration, cultural standing, and social discourses as they relate to university policies and practices (Strauss).

Fieldnotes created from participant-observation sessions (as discussed in Emerson, Fretz, and Shaw 1995) will summarize and document the researchers’ perceptions of the events observed. Fieldnotes will also be used to identify, organize, and document divergent and reoccurring themes that address the projects objectives.

Time allocations will be assessed for how students with disabilities manage their own personal, academic, and social needs throughout the day and in different dimensions of university life.

Triangulation of information obtained from archival research, interviews, participant observation, life histories, and time allocation analyses will be used to determine the specific models of action and understanding articulated by students and university staff. Each will be outlined and compared. Paying particular attention the roles and domains in which these practices and discourses occur permits discussion of both where particular identities and advocacy behaviors occur, as well as where university policies and practices limit such behaviors. Additionally, contextualization of these student’s practices and perceptions provide insight into how and why student’s identities and roles might conflict across different university domains (as observed by Low).

Assets mapping and community visioning data will be either documented as textual data or converted to textual data (in the case audio recorded community visioning meetings). The assets mapping and community visioning data will be treated in a similar fashion to audio recorded data that would be obtained from focus groups. As described earlier, information obtained from each will be used to inform recommendations made to the university.

**Significance**

This research provides insight into the willingness and desire of students with disabilities to re-appropriate a disabled label and identity in order to offer new meanings and greater awareness of what it means to be disabled and the life goals of people with disability. Analyses such as these that explore the agency and advocacy of students within specific domains of university culture and life have the potential to inform policies and practices that move us from piecemeal individual responses to the limits imposed by disability to positive and integrated institutional responses. Such university initiatives have the potential to realize, support, and build upon the strengths of all of its students.

Anticipated forums for sharing this information include scholastic journals, local presentations to academic departments, conference presentations, and recommendations to the University of Illinois.

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**Works Cited:**

Becker, Howard. 1998. “Sampling.” In *Tricks of the Trade: How to Think*
About Your Research While You’re Doing It. 67-108.


--1958 The Presentation of Self in Everyday Life. Edinburgh: University of Edinburgh,


EUI Links: After a fascinating tour of student research at and on the university, I decided to focus on a selection that was provided by an undergraduate entitled “An interpretation of the history of wheelchair basketball: An archival study of the University of Illinois Wheelchair Basketball team.” My connection to this article was two fold. The first was related to a shared research interest in campus programming for soldiers returning from war with disabilities. The second connection stemmed from my own reflections on the utility of this work and the author’s voice and analysis within it to my own research questions and foci regarding student perspectives on disability. Related to the first connection (what I would call a topical connection), I was particularly interested in this women’s use of archival documents from the university, internet, and newspaper sources in her examination of the motivations and arguments for creating and supporting wheelchair sports leagues in the post world war II era. I appreciated her integration of national attitudes (incorporating public, medical, and military discourses) on how to best integrate soldiers returning home with disabilities into the history of the experience and reception of wheelchair basketball at the University of Illinois. Similarly her future research questions and hypotheses about the relationship between national attitudes towards the Vietnam war and the waning of support for wheelchair basketball from the 1970’s on are intriguing.

The other connection I felt to this article stemmed more from my dual position of researcher and reader. Because of the author’s writing style, textual analysis, and implicit word choice, I was drawn into larger reflections about the author’s value systems and beliefs regarding war, disability, and the university’s historical and current responses and roles with regards to each. This article did not simply contain new (and extremely helpful and interesting) information and references about veterans with disabilities, it also implicitly offered me as a reader/researcher insight into the author’s own moral
sensibilities and assumptions of why particular university responses to educating and integrating soldier-students with disabilities were morally right or wrong. From her assessment, I gain a window into her sense of American history, her beliefs about patriotism, her suspicion of a tension between the U of I administration and its students, and her attitudes towards disability. I remain intrigued by her implicit advocacy of and support for historical events that valued for accessibility within the built environment, diversity of educational opportunities for students with disabilities, and agency and self-direction on the part of a person with a disability. As found in my textual analysis of the DRES website, these same values shape the current experiences of U of I’s students with disabilities. However, my own sense of disability history suggests that these values were not yet fully developed and in popular discourse within the period that she is examining. Or perhaps they were, and can be located in the articles and references that she uses!

And finally a note on authorship and identity within the EUI project. I wished that I had had more information about the author of this project. I found myself wanting more information about her interests and motivations for pursuing this particular archival analysis. What personal experiences informed this work? Did the culture of the present University inform these motivations? This exercise and final set of questions highlight the dual responsibility that we possess when turning our analytical gaze towards our “home” and producing an archive about such experiences. Reflecting on and then writing about who we are within these projects seems even more relevant and necessary given our dual roles of researcher and ethnographic subject within the EUI project.

Reflect:

Recommendations:

UIUC’s administrators, faculty, staff, and student members could benefit from a heightened awareness of disability issues. Such initiatives might build upon the efforts of student organizations as well as be developed by the university’s flagship programs for disability studies and services such as DRES and Community health and Kinesiology.

UIUC faculty should consider the important role that access to a disability history, culture, and identity can play in educating all students at the university. Faculty should be encouraged to include such histories and narrations among other mainstream and alternative accounts and foci within their course curriculum.

UIUC can strengthen its relationship with the community through increased outreach and awareness of university resources, as well as spatial designs that enrich accessibility and social interactions for individuals with multiple
abilities.

Given the prominent role that UIUC has played in the history and current promotion of wheelchair athletics and education for student’s with disabilities, the university is in a key position to serve as a leader in research on student with disabilities transition to and experience within institutions of higher education. Such research would be valuable in defining future areas for policy, service, and research development.