Beyond Access:
Understanding Students with Disabilities’ Advocacy Behaviors within Universities
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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| 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. | 1a. To describe the various domains in the student with disability’s life that are relevant to their experiences within higher education.  
   b. To document the student’s classification of roles prior to college and new roles within the university; and  
   c. To describe the process of negotiating and/or forging new relationships with peers, faculty, service providers, family members, and community members. |
| 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. | 2a. To provide a definition of agency from the perspective of students with disabilities;  
   b. To provide a definition of advocacy from the perspective of students with disabilities; and  
   c. To describe the student’s process of advocacy and the domains in which it occurs. |
| 3. To describe how university philosophies, policies, and practices regarding disability are understood and embodied or actively contested by students with disabilities within their everyday practices. | 3a. To document the university’s perceptions of disability, disability rights, and life goals for individuals with disabilities; and  
   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 affect 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 I. 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 (Sparkes 1994 as cited in Preece 1996). 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 it’s 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 for 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.

**Works Cited:**


