"Other" Accommodations: A Content Analysis of ADA-Mandated Services for Chronically Ill College Students

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Abstract

In modern Western society it is becoming increasingly important for an individual who wants professional success to earn at least a bachelor's degree. This can be difficult for the average student, but is even more of a struggle for the student with a chronic illness. Under ADA-mandated laws, colleges and universities are required to offer services to disabled students and chronically ill students often fall into this category. This study aims to investigate whether chronically ill students are marginalized by these services and the departments that offer them. In other words, are chronically ill students labeled "other" in a university environment? For many young Americans in the 21st century, obtaining a college degree is both an expectation and a prerequisite for professional success. Although college can be rigorous both academically and socially for the average student, college for a student with a physical disability or chronic illness can be significantly more challenging. The Americans with Disabilities Act (ADA) of 1990 requires institutions of higher education to offer services to individuals with disabilities (Switzer, 2003:113-114). This research investigates if there is a pattern between institutions that mention chronic illness on their websites and those that offer relevant services as part of their mandated program. The research also seeks to determine if the ADA-mandated services departments are potentially marginalizing chronically ill students through the rhetoric of their department titles and the services they offer.

The ADA defines a disabled individual as someone who, "(i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment" (Illingworth and Parmet, 2000:3). This is a broad definition which can be interpreted in many ways. The definitions of chronic illness also vary. Chronic illness scholar Susan Wendell (2001) defines chronic illness as, "illnesses that do not go away by themselves within six months, that cannot reliably be cured, and that will not kill the patient any time soon" (2001:20). No matter what the definition, if chronic illness can be medically justified as limiting one or more life activities (for which there is no official list), then under the ADA institutions of higher education are required to provide support services.

LITERATURE REVIEW

Studies on the experience of disabled students in higher education have been done using the various methods of sociological research. A review of past research reveals several themes permeate the literature, including the exploration of the experiences of students with a disability, building an identity as a disabled student, and the quality of support provided by the institution. These past studies can be translated and applied to the current study on chronically ill students.

Experience of the Student with a Disability

Many studies have focused on the experience of the disabled student at their college or university. Shevlin, Kenny, and McNeela (2004) found that students with disabilities not only struggle with rigorous academics but with their disability as well. Their research showed that students originally enjoyed the open environment provided by a college campus, but soon felt the experience was compromised by a lack of disability awareness and support for disabled students. Using qualitative data from students and quantitative data from administrators, Tinklin and Hall (1999) found that though progress has been made, disabled students are operating in a system built with innate obstacles to their participation, such as access to information and societal assumptions that all students are "normal." Fuller, Bradley, and Healey (2004) concluded that students with all types of disabilities find that learning issues related to their impairment will affect their experiences of higher education. The students may not find college to be the open welcoming environment that nondisabled students often experience. Their study also found that some students were more willing than others to ask for support, and those who did had vast

experiences about what support they received and how easy support was to access. One key point made by Beilke and Yssel (1999) related to students with "nonvisible illnesses," a category in which most students with chronic illnesses fall. A non-visible illness is an illness that manifests no obvious outward signs of impairment, such as required use of a wheelchair. Beilke and Yssel (1999) found that students who had a nonvisible impairment had twice as many obstacles as those with a visible impairment, as they needed to convince skeptics that they indeed have an impairment before they can even begin to access support. These past studies influenced the current study to record whether the accommodations needed by chronically ill students were indeed offered.

Building an Identity as a Disabled Student

Low (1996) concluded that chronically ill students are often labeled as disabled only if their impairment is visible or they disclose it, which reveals they are not a "normal" student. Low found that students then have to balance the identities of being disabled and being non-disabled, which was often difficult but necessary for students with disabilities to successfully complete their university experience. Konur (2002) found that the approach towards building an identity, even as a disabled student, is founded in society's social norms. Therefore, administrators and students need to change their attitudes towards disabled students for the programs and services offered by institutions to truly be beneficial. Moser (2000) agreed with this idea. He proposed that due to societal norms, disabled students will always be defined as "Other," with part of their identity holding the deficiencies and dependencies that are attached to that title. Jung (2003) found that part of being "Other" for disabled students in the university setting is dealing with the idea that resources are being wasted on their education. Brueggemann, Garland-Thomson, and

Kleege (2005) discussed how the "mainstream" culture of a college campus forces a disabled student to be labeled as "Other" and oftentimes accept that as a positive label without challenge.

Shiu (2001) found that chronically ill students of any age are constantly reminded of their impaired status due to the need for special treatments and regimens. Society's norms dictate that a disabled person cannot necessarily be a successful, productive member of society, especially in certain fields, so the money spent on accommodations in education is money wasted. When this idea dominates the climate at a university, Jung found that this stigma influences students' identity formation. These past studies influenced the current study to look at the titles of the ADA compliance departments to determine how they "label" students.

Quality of Institutional Support

Graham-Smith and Lafayette (2004) examined the quality of services offered to disabled students by an institution. They found that resources are used more effectively and the needs of individual students are met more acutely when the services offered are based on the students' perspective. Singh (2003) also conducted a study of the quality of support of services offered at institutions of higher learning, finding that it is not always easy for institutions to accommodate students with disabilities even though federal law requires them to make accommodations. Jung (2003) expanded on this idea, finding that oftentimes institutions resisted the improvement of accessibility services to maintain the status quo of the institution. Jung also found that universities' and colleges' decisions to accommodate students are often based on precedence of previous accommodations.

In a study of chronic illness and employment, Munir, Yarker, and Haslam (2007) found that institutional support is better implemented when the managers and upper level administrators are well-trained in provision of support. This can easily be translated to higher education, concluding that administrators and faculty need to be well-trained in implementation of support in order to better accommodate disabled and chronically ill students. Zaitsev (2010) found that higher education better serves disabled students when they are in a "culture of support," which includes comprehensive accommodations and support in all aspects of university life. This leads to the current study's investigation of services offered, and mention of chronic illness, as a means of building a "culture of support."

FEMINIST DISABILITY THEORY

Feminist theory traditionally discusses the marginalization of women in society. Feminist theorist Simone de Beauvoir (1953) argued that women are often regarded as inferior and labeled as "other" in Western society. She states, "…what peculiarly signalizes the situation of woman is that she – a free and autonomous being like all human creatures – nevertheless finds herself living in a world where men compel her to assume the status of "Other" (p. xxix). Similarly, the disabled live in a world where they are considered abnormal. Being female and being disabled are quite similar in that both identities force an individual to live and operate in a world not built for *their* norms.

Rosemarie Garland-Thomson (2002) proposes not a new theory of feminism but a new lens through which to view disability. Garland-Thomson says, "Most fundamentally, though, the goal of feminist disability studies...is to augment the terms and confront the limits of the ways we understand human diversity, the materiality of the body, multiculturalism, and the social

formations that interpret bodily differences" (2002:3). These topics are all a part of current feminist theory, but Garland-Thomson propose that using a disability studies lens to further analyze these topics can only add to the richness of feminist theory.

Disability and gender are both concepts that reach deep into our society and run throughout our institutions. Garland-Thomson (2002) is quick to clarify that feminist disability theory does not merely focus on women with disabilities. It relates across society to structures that intermix to create our societal norms. Garland-Thomson states, "Integrating disability clarifies how this aggregate of systems operates together, yet distinctly, to support an imaginary norm and structure the relations that grant power, privilege, and status to that norm" (2002:4).

Being female is often considered an unnatural state of humanity. In *The Second Sex* (1953), de Beauvoir quotes the philosopher Aristotle, "The female is a female by virtue of a certain *lack* of qualities...we should regard the female nature as afflicted with a natural defectiveness" (p. xvi). The same is true for the disabled, for they are also considered defective. The two labels are joined by their "otherness." "Others" are created when they do not fit into the ideals of a society. Garland-Thomson discusses this notion in what she calls, "the ability/disability system." She says:

The disability/ability system produces subjects by differentiating and marking bodies. Although this comparison of bodies is ideological rather than biological, it nevertheless penetrates into the formation of culture, legitmating an unequal distribution of resources, status, and power within a biased social and architectural environment. (2002:5)

In other words, the ideal of Western society that one should be a young, healthy, white male has no biological standings. Garland-Thomson is drawing upon ideas brought from Wendell's 1989 piece, "Toward a Feminist Theory of Disability." Wendell discusses how this aforementioned ideal plays a part in society's every day:

Much of the world is also structured as though everyone is physically strong, as though all bodies are "ideally shaped," as though everyone can walk, hear and see well, as though everyone can work and play at a pace that is not compatible with any kind of illness or pain, as though no one is ever dizzy or incontinent or simply needs to sit or lie down. (1989:111)

The Western ideal college student works and lives at a "go, go, go!" pace. The university institution is part of the world where Wendell sees the aforementioned structural problems. Garland-Thomson discusses the body and appearance as a domain of feminist disability theory.

She states:

The medical commitment to healing, when coupled with modernity's faith in technology and interventions that control outcomes, has increasingly shifted toward an aggressive intent to fix, regulate, or eradicate ostensibly deviant bodies...the ideology of cure directed at disabled people focuses on changing bodies imagined as abnormal and dysfunctional rather than on changing exclusionary attitudinal, environmental, and economic barriers. (2002:14)

This idea builds on the aforementioned ability/disability system. Western society is built for the "abled" and instead of trying to fix the system and structures to accommodate those labeled "disabled," society often tries to fix the disabled person himself. Universities set forth policies of "accommodation" instead of reviewing existing policies that create and enforce barriers. Jeffrey C. Kirby (2004) further comments on this idea, stating, "On this view, efforts should be directed at modifying existing mobility communication systems and institutional practices to eliminate barriers and allow disabled individuals to engage and participate in the cooperative framework,

rather than be directed at preventing or fixing the motor, sensory, and cognitive "deficits" of disabled individuals" (2004:233). Overall, in her discussion of the body and appearance, Garland-Thomson is stating that not all of disability, like not all of femininity, is a biological construct. Disability is a social construct.

The physical and psychological structures of colleges and universities are evidence that the world is built for the "abled." Higher education is built around the norm that all students can function in a pressured environment. These norms include students attending several classes a day and spending a good majority of their free time studying. This is often impossible for students with chronic illnesses, whether it be due to severe pain, exhaustion, or hospitalizations. Institutions are legally bound to offer students programs and services to help make them more "abled." Yet by the necessity of these services, the institutions are labeling chronically ill students as "other." Jung (2003) states, "The process of accommodation – which involves providing special exceptions to the ordinary rules...will be experiences in combination with social stigma based on the perception that disabled students are inherently different from 'ordinary' students..." (p.186). Disability theorists are aware there should be a restructuring of the expected norms in higher education so that chronically ill students are no longer stigmatized. In "Extraordinary Stories: Disablity, Queerness, and Feminism," (2002) Bente Meyer comments on Garland-Thomson's perspective, saying, "For Thomson, the essence of bodily repression and stigmatization rests in the corporeal otherness represented by extraordinary bodies, particularly those that do not conform to the self-governing, standardized individualism defined as normative" (2002:169). Meyer's idea can be applied to chronically ill college students. These students are not "normal" by their own physical bodies and the standards of higher education make this a social disability.

Western society's normative view of disability as a biological construct instead of the social construct Garland-Thomson and other feminist disability theorists see it as, has resulted in negative consequences for chronically ill students. These students need assistance that is often inadequately provided due to attitudes toward the disabled, especially the invisibly disabled. In "Toward a Full Inclusion Feminism: A Feminist Deployment of Disability Analysis," Judy Rohrer (2005) theorizes that nondisabled people and institutions often have to provide services and assistance to chronically ill students without realizing why it is necessary or just. Rohrer helps to further explain Garland-Thomson's complex view of disability, especially for the chronically ill, as being a biological impairment yet a social handicap. Rohrer quotes the historian Paul K. Longmore, who says, "We are dis-abled. We live with particular social and physical struggles that are partly consequences of the conditions of our bodies and partly consequences of the structures and expectations of our societies, but they are struggles which only people with bodies like ours experience" (2005:38). This means that as long as the chronically ill student qualifies under law as disabled, then colleges and universities must provide assistance. No one at the institution, including other students and faculty members, can judge if someone is "disabled enough" for assistance and accommodations. This is why it is important to study the ADA-mandated service departments and their services.

METHODOLOGY

This study looks at the ADA-mandated services offered to chronically ill students at colleges and universities in the state of Illinois. Information about services was gathered by a content analysis of the institutions' websites. Neuman (2007) defines content analysis as, "a technique for examining information, or content, in written or symbolic material" (2007:20).

Websites are an accessible source of information and are commonly becoming the most popular way for perspective students to find information about institutions. Websites are the "face" of an institution in our modern society.

Illinois was chosen because the institutions in that state provide a variety of demographics, including school affiliation, cost of tuition, and geographical setting. The schools were found through a convenience sample on the College Board website, by clicking on the "college search" option and then the "college matchmaker" option. "No preference" was selected for every following preference option except for "4 year institution," "undergrad housing must be provided," and "in Illinois." Any specialty or technical schools were discarded from the 78 resulting institutions leaving a sample of 48 institutions. Out of this sample, the researcher was unable to locate information on ADA-mandated services for 4 schools; these schools were discarded leaving a sample of 44 institutions.

Schools were first coded for the available demographics listed. The institution's geographical setting was coded, and 7 schools were found to be rural (population of 10,000 or less), 23 schools were found to be suburban (population of 10,001-99,999), and 14 schools were found to be urban (population of 100,000 or more). The institution's affiliation was coded with 16 schools found to be Protestant, 7 schools found to be Catholic, 11 schools found to be Independent and 10 schools found to be Public. The cost of undergraduate tuition for one year, not including housing or fees was also coded and 12 schools were found to have low (\$15,000 or less) tuition, 24 schools to have medium (\$15,001-\$30,000) tuition, 5 schools to have high (\$30,001 or more) tuition and 3 schools did not have tuition information available.

The title of the department dealing with ADA-mandated services was also recorded. The rhetoric in the title was coded and divided into five categories based on the main word in the title. The categories were, "Disability," "Access/Ability/Accommodation/Assistance," "Learning/Academic," and "Success/Excellence." Variations on the tense and use of these words were noted in coding. These categories were chosen because the rhetoric used forces students to self-identify as they ask for support. In effect, the titles of the departments place a label on students receiving their services. These labels can potentially have a negative effect on students. Susan Wendell (1996) discusses labels, saying:

I believe it is because our own languages so often betray us –by offering so many ways of derogating us, by containing the assumption that we are 'Other,' and failing to describe our experiences...Part of asserting our similarities to people without disabilities is demanding that we not be set apart by disparaging and/or unnecessary labels, and that the words used to describe or refer to us be as respectful as the words used to describe or refer to nondisabled people. (1996:77)

Types of programs and services listed as offered for disabled and chronically ill students were coded. These services were placed into categories such as, "Exams," which includes extra time, alternate environment, readers, scribes, rest periods, and use of a computer, "Technology," which includes readings on CD, audio-equipment loans, adaptive software loans, and access to copy machines, " Housing," which includes wheelchair access, air conditioning, exemption to on-campus housing requirements, and single rooms, "In-Class," which includes change of physical environment, note-takers, American Sign Language interpreters, and preferential seating, "Registration," which includes assistance with strategic scheduling, priority scheduling and course substitution, "Absences," which includes medically based excused absences and makeups and extensions, "Meals," which includes frequent meals or permission to eat in class, "Parking," which includes access to handicapped parking and reserved parking, and "Other," which includes reduced course load, peer tutoring, route training and accessible transportation, elevator and lift keys, and advocacy and counseling.

It is also noted whether chronic illness (including terms: "chronic medical conditions," "medical disabilities," "neurological disorders," "health impairments," "invisible conditions," "episodic disorder," "health related disability," "progressive health conditions," "disorder, condition, or syndrome," "mobility, systemic, or disease related disabilities," and "physiological disorder, or condition") is specifically mentioned in the descriptions of the services offered or on the department's web page. There are general types of service categories offered to disabled students but some are more applicable than others to chronically ill students due to their special needs. Royster and Marshall (2008) state, "...students with chronic illness require accommodations that must continually be negotiated, adapted, and arranged...Traditional college and university programs do not systematically offer students accommodations that take into account the unpredictable nature of their chronic conditions" (2008:121). Each chronically ill student requires different accommodations even if they have the same illness. It is not a "one size fits all" situation.

FINDINGS

The purpose of this research was to determine whether chronically ill college students are marginalized by the ADA-mandated services offered. The study used cross tabulations to determine if mention of chronic illness on the institution's website had any correlation to the title of the department or the services offered by the institution. The study found as shown in Table 1,

that 18 schools mentioned chronic illness on their website while 26 schools had no mention of chronic illness.

Did the Institution Mention Chronic Illness?	Frequency	
No	26 (59.0%)	
Yes	18 (40.9%)	
Total (N=44)	44 (100.0%)	

Table 1. Mention of Chronic Illness on Institution's Website

A cross tabulation was performed to determine if the mention of chronic illness was

related to the rhetoric in the title of the department. Mention of chronic illness did not matter at all in regards to titles including the rhetoric, "Learning/Academic,"

"Access/Ability/Accommodations/Assistance," or "Other." Departments using the term,

"Disability" were less likely to mention chronic illness by a margin of 23.8 percent. Departments using the rhetoric of "Success/Excellence," were less likely to mention chronic illness by a margin of 60 percent. This is a significant margin which may indicate a negative viewpoint

towards chronically ill students by these institutions.

Table 2. Mention of Chronic Illness According to Department Title

Department Title	Mention of Chronic Illness		Total (N=44)
Department Title	Yes (n=18)	No (n=26)	10tal (11-44)
"Disability"	8 (38.1%)	13 (61.9%)	21 (47.7%)
"Learning/Academic"	6 (50%)	6 (50%)	12 (27.3%)
"Success/Excellence"	1 (20%)	4 (80%)	5 (11.4%)
"Access/Ability/Accommodations/Assistance"	2 (50%)	2 (50%)	4 (9.1%)
Other	1 (50%)	1 (50%)	2 (4.5%)

As shown in Table 3, schools offering registration services were more likely to mention chronic illness by a margin of 53.9 percent and all schools offering absences services mentioned chronic illness on their website. A statistically significant relationship (p < .05) exists between

the mention of chronic illness and the services offered. There was no correlation between offering in-class services or other services and mention of chronic illness.

Table 3. Mention of Chronic Illness According to Services Offered

Service	Mention of Chronic Illness		Total Number of Service Mentions
	Yes	No	(N=150)
Exams (n=35)	17 (48.6%)	18 (51.4%)	35 (23.3%)
In-Class (n=34)	17 (50.0%)	17 (50.0%)	34 (22.7%)
Technology (n=25)	13 (52%)	12 (48%)	25 (16.7%)
Other (n=20)	10 (50.0%)	10 (50.0%)	20 (13.3%)
Registration (n=13)	10 (76.9%)	3 (23.1%)	13 (8.7%)
Housing (n=11)	5 (45.5%)	6 (54.5%)	11 (7.3%)
Parking (n=7)	2 (28.6%)	5 (71.4%)	7 (4.7%)
Meals (n=3)	1 (33.3%)	2 (66.7%)	3 (2.0%)
Absences (n=2)	2 (100.0%)	0 (0.0%)	2 (1.3%)

Overall, the data showed that chronically ill students are grouped into a category of "disability" that does not necessarily fit them. The rhetoric used in the department titles place students at a socially constructed disadvantage due to the labeling provided. The services offered may in some instances help a chronically ill student but they were not constructed for that purpose and therefore often marginalize the chronically ill.

DISCUSSION

The types of accommodations implemented by institutions due to ADA mandates are generally determined by the institution (Kiuhara and Huefner 2008). The data show, by a lack of mention of chronic illness in over half the studied institutions, that chronically ill students in higher education are marginalized. While these students might be included under the umbrella term of "disability," this does not address the special needs of a chronically ill student.

Jung (2002) states, "...chronic health conditions fail to properly fit the institutional framing of disability. Unpredictable periods of exacerbation and remission and the experience of pain and fatigue...are difficult to gauge and measure objectively. Changing symptoms disrupt the more prevalent understanding of disability as a fixed or constant physical condition" (2002:191). Therefore, offering services like a classroom's change of physical environment or adaptive software are not often relevant to the chronically ill student. Students do benefit from such services as priority registration, so as to schedule a course load that can accommodate for periods of rest, and students also benefit from excused absences for when they are hospitalized or simply too ill to attend class. However, these necessities increase the marginalization of the chronically ill student because they directly conflict with the ideal student who can attend all classes with full energy. Also, instead of focusing on making higher education more open to the chronically ill lifestyle, institutions try to fix the chronically ill student to fit into the social norms. This relates back to the theory of feminist disability. Society also tries to fit women into men's norms instead of reworking the societal structure to accommodate women. Liz Crow (1996) describes the phenomenon, stating, "Massive resources are directed into impairment-related research and interventions. In contrast, scant resources are channeled into social change for the

inclusion of people with impairments" (p. 215). The research showed that institutions that mention chronic illness are aware of this fact since the majority that offer these types of services also mentioned chronic illness.

Rhetoric is very controversial when dealing with so-called disabilities because of the negative connotation that can accompany that term. Some students with a chronic illness will identify as disabled outside the institution, while others will not. Yet either way, the majority of chronically ill students must utilize disability services in order to complete their higher education (Jung, 2003:92). The rhetoric used in the titles of the departments offering ADA-mandated services often force this disabled identity upon students. This research found that departments using the term "disability" were far less likely to mention the term chronic illness. This is perhaps because those departments assumed that chronic illness was implied under the umbrella term. The implications of this assumption are that it is more difficult for chronically ill students to pass for "disabled," as they do not fit the stereotypical picture. Chronically ill students often do not possess visible symptoms (such as use of a cane or wheelchair) and therefore often have to "prove" their illness and justify their use of services by doctor's notes or test results more so than a visibly disabled student. This process stigmatizes the student and places them into an identity of "other." They must admit that their body is neither up to our Western culture's ideal of normal nor our ideal of disabled. Susan Wendell (2001) explains this phenomena stating:

Moreover, those of us with chronic illnesses do not fit most people's picture of disability. The paradigmatic person with a disability is healthy disabled and permanently and predictably impaired. Both attitudes toward people with disabilities and programs designed to remove obstacles to their full participation are based on that paradigm. Many of us with chronic illnesses are not obviously disabled; to be recognized as disabled, we have to remind people frequently of our needs and limitations (Wendell, 2001:21).

The study's finding that the institutions with department titles using the terms "access/ability/accommodations/assistance," or "learning/academic," are just as likely as not to mention chronic illness is of interest. This finding could signify that institutions using these terms are equally likely as not to consider chronic illness a disabling issue of social construct that would need accommodations. Similarly, they are just as likely as not to view chronic illness as an issue directly affecting learning styles and procedures. Overall, this finding could imply that these institutions are equally likely as not to operate out of a medical model of disability as a social model of disability in terms of chronic illness.

Overall, the disability and chronic illness communities have moved toward the social model of disability, where disability is a social construct created by social barriers rather than physical impairments. Hughes and Paterson (1997) explain the movement, stating, "The medical view that social restrictions for disabled people were a consequence of physical dysfunctions was overturned by a radical move which argued that people with impairments were disabled by a social system which erected barriers to their participation" (1997:328). Chronically ill students are not inherently incapable of participating in the normal college lifestyle. It is the social barriers built through years of "able-ism" that create chronically ill students as "other."

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