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# Student and Faculty Awareness and Attitudes about Students with Disabilities

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## Research Articles

**Abstract:** Every year an increasing number of students with disabilities are graduating from high school and entering into postsecondary education. In an effort to assess the university climate for students with disabilities a survey was conducted on a large Northeastern campus. The survey focused on the attitudes, beliefs, and knowledge of university students and faculty on disability-related issues. Results are presented from undergraduate, graduate, and faculty perspectives. Most students and faculty report positive attitudes and interactions with students with disabilities, however these interactions are often limited and awkward. Disability issues are not often presented in the classroom content and the majority of faculty do not announce the availability of accommodations in the classroom. Implications for postsecondary institutions are explored.

**Key Words:** higher education, faculty, disability

\*Editor's note: this article was anonymously peer reviewed.

### Introduction

According to the U.S. National Center for Education Statistics (2006) eleven percent of undergraduates reported having a disability in 2003–2004. One in five youth with disabilities that are out of school are currently attending postsecondary education. The rate of people with disabilities attending postsecondary school is less than half that of their peers in the general population (Wagner, Newman, Cameto, Garza, & Levine, 2005). Enrollment in two or four year degree-granting institution for people with disabilities has increased steadily (Gerald & Hussar, 2002). College enrollment includes

close to half a million students with disabilities (Wagner et al., 2005).

Over the past four decades, there have been several laws passed in the United States to protect students with disabilities from discrimination by institutions of postsecondary education. These laws enhance the opportunities available for people with disabilities and allow them to participate more fully in society. For example, Section 504 of the Rehabilitation Act of 1973 (504) applies to all colleges that receive federal funds, and The Americans with Disability Act (ADA) of 1990 applies to employers, government entities, such as state universities, and private entities. Before the passage of the ADA, various research studies showed that negative attitudes towards persons with disabilities created obstacles that did not allow people with disabilities to participate in society (Bordiere, & Drehmer, 1986; Elston & Snow, 1986; Minskoff, Sautter, Hoffman, Hawks, 1987).

The ADA requires colleges to make reasonable accommodations for students with disabilities. This has led to changes in architectural barriers on campuses as well as the provision of technical supports in the form of aids, readers, and interpreters. Faculty members at many universities are encouraged to make reasonable changes for students with disabilities. Under the ADA, faculty members must be providing these accommodations, however, few studies have examined if faculty are doing so. In this study, students on campus were asked to provide their perceptions of how faculty members incorporate disability education into their curricula and if they provide accommodations to students with disabilities. In addition, graduate students and faculty members were asked if they provided accommodations in the classroom and

if inclusion of disability-related topics were incorporated into classroom discussion.

Unfortunately, the guarantee of federal laws for non-discrimination, equal opportunity, and reasonable accommodations for students with disabilities in higher education omits the guarantee for full participation or full inclusion in higher education. Few studies have looked at student perceptions of full inclusion in postsecondary education.

Students with disabilities during the school-aged years are protected by laws such as the Individuals with Disabilities Education Act (IDEA) which requires schools to create Individualized Education Plans. No such plan exists for students when they progress into the college years. According to the U.S. General Accounting Office (1999) youth with disabilities are more likely to enter employment instead of continuing on to postsecondary education after high school. The lack of support during postsecondary schooling and the perception that other students and faculty view disabled students negatively can often contribute to a difficult college experience (Burgstahler, 1994). Negative attitudes toward people with disabilities have been related significantly with a decrease in full usage of skills and abilities, a lowered self-concept, and negative job related outcomes (Madaus, Gerber, & Price, 2008; Piggott & Houghton, 2007).

Students with disabilities are concerned about faculty's lack of awareness of their requirements and often report that professors fail to meet their needs in the classroom (Moore & Nye, 1986). Unfortunately, the information we do have about college students' perceptions of their peers with disabilities is sparse. Hergenrather & Rhodes (2007) reported that undergraduate students have positive attitudes towards persons with disabilities pertaining to interaction with them in the workplace, marriage and dating. However, this study did not look at the attitudes towards students with disabilities in the classroom or university campus.

Grand, Bernier, and Strohmer (1982) discuss the importance of the social context and its influence on attitudes towards people with disabilities. Attitudes towards people with disabilities were different depending on social context. For example, attitudes towards those with disabilities in the workplace were more favorable than in the context of dating or marriage (Grand, Bernier, & Strohmer, 1982). Research is lacking on attitudes towards people with disabilities in a variety of contexts. This information would assist in intervening and modifying attitudes appropriately depending on the context.

There are few research studies that look at faculty attitudes towards students with disabilities in postsecondary education and their willingness to provide accommodations (Fonosch & Schwab, 1981). These early studies found that faculty attitudes are more positive when faculty members have previous contact and more information about students with disabilities (Aksamit, Leuenberger, & Morris, 1987; Sedlacek & Stovall, 1983). Only a few other studies undertaken since 1987 studied faculty awareness in relation to students with disabilities in higher education, and they each have their limitations. For example, one study had a small sample size of nine faculty members (Cook, Hennessey, Cook, & Rumrill, 2007), and another study had 41 faculty members (Burgstahler, Duclos, & Turcotte, 2000). Both studies used a focus group methodology. There are a few dissertations that focus on faculty attitudes towards students with disabilities (Badgett, 1993; Benham, 1995; Lewis, 1998; McGee, 1989; Williamson, 2000). Faculty attitudes towards students with disabilities in postsecondary institutions are one of the important contributors to the success of students enrolled (Rao, 2004). Faculty lack information about the rights and accommodations necessary for students with disabilities, and can have negative attitudes about including students with disabilities in academic programs. Professors are particularly reluctant to include students with learning disabilities (Leyser, 1990)

and have little knowledge of the characteristics and needs of students with this type of disability (Dodd, Fischer, Hermanson, & Nelson, 1990).

The purpose of this study was to determine the attitudes, beliefs, and knowledge of university students and faculty on disability-related issues in the university context, including opinions and interactions with students with disabilities and how disability issues are accommodated and addressed in the classroom. The study occurred in a large state university in the Northeast.

## Methods

Two surveys were conducted at the same university: 1) survey of undergraduate students and 2) survey of faculty and graduate students. The surveys consisted of between 28 and 33 multiple choice questions that focused on three main areas: 1) Information on interactions with individuals with disabilities; 2) Opinions about disability-related issues; 3) How well the community/classroom treats and provides for individuals with disabilities. The following section describes the methodology and sample for the undergraduate survey and then the methodology and sample for the faculty and graduate survey.

### Undergraduate Student Survey

The first survey was administered in March, 2006 to a total of 881 undergraduate students or 4% of the total student body (191 freshmen, 258 sophomores, 241 juniors and 191 seniors). The university student body for Fall 2007 was 20,846 undergraduate students. The survey was an intercept survey, which is an accepted methodology that is frequently used in many fields of study, including consumer marketing research (Wright, Gendall & Lewis, 1999; Jin & Gu Suh, 2005), the social sciences (Spooner, Bishop & Parr, 1997), and public health (Miller et al., 1997). Interviewers intercepted students and administered the survey at a wide variety of locations on campus (e.g., dining halls, the Stu-

dent Union, the Co-op, the library, and various campus cafes) during different days of the week and times of the day to capture a cross-section of undergraduate students at the university.

The undergraduate sample of 881 students was comprised mainly of students who lived on campus (79%), and their years in school were fairly evenly distributed (Freshman-19%, Sophomores-23%, Juniors-27%, and Seniors-32%). More than half of the undergraduate respondents were Liberal Arts and Sciences students. Only a small percentage of undergraduate students considered themselves to have a disability (6%), yet almost half (45%) of them reported having close friends or family members with a disability.

A review of the data from the student survey across class groups (i.e., freshmen, sophomore, juniors and seniors) shows the findings to be somewhat similar. The freshmen surveyed had a higher incidence of uncertainty in their responses ("Not Sure"), probably given their limited experience on the university campus. To ensure that overall results are representative of the total population of students based on college, a weight was designed to account for differences between the number of students observed in each category and the estimated population parameters. Results presented are based on weighted analysis to account for students in different majors and class years.

### Faculty and Graduate Student Survey

A second survey, at the same university as the previous undergraduate survey, was conducted of faculty and graduate students. The survey was created and administered via the Web in December, 2006 and January, 2007. All current university faculty members and graduate students, on all campuses including the Law School and Medical School, were sent email invitations with a link to the online survey. The total population of graduate student body for Fall, 2007 was 7,831 graduate students and 1,766 faculty members.

A total of 2,056 faculty and graduate students completed the survey. Thirty-six percent of respondents were faculty members, 38% were graduate students without teaching responsibilities, and 25% were graduate students with teaching responsibilities. The faculty and graduate student survey showed that 40% of respondents were from the College of Liberal Arts and Sciences, with 11% from the School of Education, 10% from the School of Medicine, 9% from the School of Business Administration and the remainder from a variety of different schools and programs. Only a small percentage of faculty members and graduate students with and without teaching responsibilities considered

naire such as this, which solicited respondents' opinions on people with disabilities, there was a concern that people might answer questions with a positive bias. The Marlowe-Crowne Index contains 10 true/false questions. An example of two of the questions is: I have never intensely disliked anyone, and I am always courteous even to people who are disagreeable. If the respondent answered true to one of these questions then they received one point, scores ranged from 0 to 10 with 10 being a high score, indicating high social desirability. The index was calculated and run by every question in the survey to see if there were discrepancies across the responses.

**Table 1. Feelings towards Students with Disabilities**

	Undergraduate	Graduate	Faculty
<b>Admiration</b>			
Often	24%	27%	29%
Occasionally	48%	52%	54%
Never	17%	14%	9%
Not Sure	10%	8%	9%
<b>Pity</b>			
Often	16%	12%	5%
Occasionally	63%	57%	55%
Never	17%	26%	33%
Not Sure	4%	5%	7%
<b>Awkwardness/Embarrassment</b>			
Often	3%	5%	3%
Occasionally	63%	52%	58%
Never	29%	37%	35%
Not Sure	4%	5%	5%

themselves to have a disability (5%, 7%, and 5% respectively), and about half (51%) of them reported having close friends or family members with a disability.

The faculty and graduate student survey included the Marlowe-Crowne Social Desirability Index (Crowne & Marlowe 1960) which was calculated and run against each survey question. This scale measures peoples' internal desire to answer questions in a way that they feel their answers will be viewed favorably. On a question-

Social desirability had little effect on the overall results of the survey. It did have a slight impact on the following two questions: (1) When you encounter a person who appears to have a disability, how often do you feel a) awkward or embarrassed, and b) pity. People who had a high level of social desirability were found to be more likely to answer as never having these feelings as opposed to those with low social desirability; (2) when talking with a person with a disability, I find myself looking away more than you usually do in conversation, agree or dis-



**Table 2. Interactions with Students with Disabilities**

	Undergraduate	Graduate	Faculty
Close friends or family members with a disability	45%	47%	58%
Co-worker with a disability	n/a	22%*	34%
Interact almost every day with someone with a disability during work hours	n/a	8%*	20%
Student with a disability in their classroom	n/a	39%*	52%
No social interaction with people with disabilities (either outside of class or work)	45%	45%	41%
Social interaction with 3 or more individuals with a disability in past month	n/a	7%	8%

\*only graduate students with teaching responsibilities are reported

agree. People with a high social desirability score were more likely to say that they do not look away more compared to those with a low score.

## Results

A total of 881 undergraduate students and 2,056 faculty and graduate students participated in the survey.

### Opinions & Interactions with Students with Disabilities

An overwhelming majority of undergraduates (72%), graduate students (79%), and faculty members (83%) polled, occasionally or often felt admiration for persons with disabilities. The majority of undergraduates, graduate students and faculty reported feelings of pity (students 79%; graduate students and faculty 60%), awkwardness, and/or embarrassment (students: 66%; graduate students and faculty 61%), often or occasionally when encountering a person with a disability (Table 1). Fifty-four percent of the undergraduates surveyed reported having been taught how to approach and interact with individuals having disabilities.

Students and faculty voiced concern that their actions or conversation might have been inappropriate. Almost five in ten students indicated that they were never enthused about encounters with people who are disabled. Nearly eight in ten (79%) faculty and graduate students

said they did not find themselves looking away more in conversations with a person with a disability. When interacting with speech-impaired individuals, one third of students (34%) and 18% of faculty and graduate students reported that they were unsure if it is helpful to finish their sentences or supply words. Twenty six percent of students and 18% of faculty and graduate students indicated they were unsure of how to respond to an assistance dog, such as whether it was appropriate or not to pet the animal.

These concerns and behaviors might be the result of the limited interaction of students and faculty with people with disabilities (Table 2). Although almost half of the undergraduate students surveyed (45%) had family or friendship ties with persons having disabilities, the remaining 55% had limited relationships with individuals with disabilities. Faculty members reported that 34% had a co-worker with a disability, 20% interacted with someone with a disability almost every day in the workplace and 52% reported having a student with a disability in at least one of their classes.

Both students and faculty recounted limited interaction with students with disabilities. Students and faculty were asked about the number of individuals with disabilities with whom they socialized outside of classroom time or outside of work time in the last 30 days. Close to half of the undergraduates surveyed (45%) and almost

half of faculty (41%) and graduate students (45%) reported “none,” and 8% of faculty and 7% graduate students indicated that they had socialized with three or more individuals having disabilities in the past month (Table 2).

There was more uncertainty related to equity in social opportunities (joining clubs, attending social events, etc.); 45% of the undergraduates and 34% of faculty and graduate students suggested that individuals with disabilities were treated fairly, 20% of students and 7% of faculty suggested there was not equitable treatment, and over a third (35%) of the students and 59% of faculty were not sure. Almost half of the undergraduate respondents (49%) and 18% of faculty and graduate students felt that the university is doing a “poor” to “fair” job including individuals with disabilities in social organizations and co-curricular activities. Twenty five percent of undergraduates, graduate students and faculty suggested university efforts are “good” to “excellent,” while 25% of undergraduates and 58% of graduate students and faculty answered that they were not sure.

### **Disabilities in the Classroom**

The efforts of the university to provide accommodations to those with disabilities were perceived positively. As such, 87% of the undergraduates surveyed believed these efforts did not give unfair advantage to students with disabilities. When asked more specifically about academics and social opportunities, a clear majority (63%) of undergraduates believed that individuals with disabilities received fair treatment in the academic arena.

When faculty were asked about individuals with disabilities being treated fairly in the classroom, 55% of faculty and graduate students reported that they were treated fairly, yet 40% were not sure. Faculty and graduate students with teaching responsibilities were polled about their use of the university’s Academic Accommodations Policy for students with disabilities. Faculty members were more likely to have ap-

plied this policy (43%) than graduate students (28%) (Table 3).

Thirty-two percent of undergraduate students had no professors this semester who asked, either through announcements or through a syllabus, about accommodations in the classroom (Table 3). However, 46% of faculty members and 53% of graduate students who teach waited until the end of class for a student with a disability to approach them about accommodations, 18% of faculty and 35% of graduate students announced the availability of accommodations during the first class of the semester, and 18% of faculty and 34% of graduate students included this policy in their class syllabus (Table 3).

The majority of faculty (65%) and half of the graduate students (51%) who teach have provided accommodations for students with disabilities. Of these, 71% said that it required little to no extra preparation time to make these accommodations available. A very small percentage (7%) viewed making the accommodations inconvenient, as they created disruptions to class flow and caused feelings of unfairness in other students.

More than half (65%) of the undergraduates felt that courses and classroom discussions at the university had not prompted greater awareness of disability-related issues. Sixty-five percent of faculty and graduate students did not include discussions that promoted awareness of disability-related issues in their classes, and about half (45%) felt that disability-related topics were not relevant to their class. Of the 24% who included these topics in class discussion, 36% said they worked these issues into one or more classes each semester.

The majority of faculty and graduate students (88%) did not think they should do anything different for students with disabilities compared to what they are doing now. However, when asked what the university can do to make the campus more hospitable for individuals with disabilities, 37% reported better accessibility,



22% thought more support and accommodations should be given, 19% reported transportation improvements, 13% cited improvement in the Center for Students with Disabilities, 6% thought increasing disability awareness and 3% said there should be more opportunities for people with disabilities overall.

## Discussion

The ADA of 1990 requires that all state universities make reasonable accommodations to students with disabilities. Under the ADA, faculty members must provide students with disabilities accommodations. Fewer than half of the faculty members in this study and only 28% of graduate students reported applying the

are not receiving the required accommodations. In another study, students with disabilities reported that most professors failed to meet their needs in the classroom (Morre & Nye, 1986). More research is needed to ask disabled students how their needs are being met in the university.

The university does have a disability resource center that serves to enhance the post secondary experience for students with disabilities. The university also has a variety of outreach programs for students, so it is unclear if students would not otherwise know about services available to them if faculty members did not announce it in class. However, it can be argued that by mentioning the availability of supports in class or including it in the syllabus

**Table 3. Communication of Availability of Accommodations in the Classroom**

	Undergraduate	Graduate*	Faculty
Have applied the university Academic Accommodations policy for students with disabilities	n/a	28%	43%
No professors in any class announced the availability of accommodations in the classroom and it was not in the syllabus	32%	n/a	n/a
Waited until the end of class for students to approach them if they needed an accommodation	n/a	53%	46%
An announcement was made in the first class that students with disabilities can make arrangements	n/a	35%	18%
The availability of accommodations was included in the syllabus	n/a	34%	18%

\*only graduate students with teaching responsibilities are reported

University's Academic Accommodations Policy. One third of undergraduates reported that professors did not mention the availability of accommodations either through announcements or in the syllabus. About half of the faculty and half of the graduate students did not announce or include the policy in their syllabus and instead waited for students with disabilities to approach them. This does not necessarily indicate that faculty are not providing accommodations when requested. However, if students do not perceive the availability of accommodations, then it is possible that many disabled students

students feel more comfortable approaching a professor and requesting accommodations. There is no university policy that mandates that all faculty members include a section about accommodations on their syllabi. The disability resource center does offer training and technical assistance to faculty; however the training is not mandatory, and is provided mostly as it is requested by a department. Recommendations for moving forward are to integrate disability training into the human resources process for new hiring of faculty at the university, or to create online modules for faculty to access instead

of in-person workshops. Some of the topics should include legal responsibilities, universal design for instruction, disability issues and disability culture.

It has been suggested that transition planning should be included for students with disabilities planning on entering into higher education (Gil, 2007). Transition planning would include collaboration between secondary educators and postsecondary service providers, helping students bridge the gap between high school and higher education (Gil, 2007). This would ensure that students, parents, and professionals at higher education institution have the information necessary to make informed decisions. A collaborative approach to transition services involving all key players will ensure that students are knowledgeable about the postsecondary institution and services available and how to advocate and represent their needs effectively to their professors. In addition it will benefit postsecondary professionals by helping them to accommodate and provide full inclusion services to those students with disabilities.

More than half of faculty and graduate students who teach in this study do not include disability-related topics in the classroom through discussions or classroom activities, and about half feel that disability-related topics are not relevant to their class. Increasing awareness and creating a culture of understanding and inclusion for students with disabilities must begin in the classroom. The inclusion of topics and discussion about disability issues will create a comprehensive curriculum for students. These findings call for a change in the curriculum available for students including more classes about disability topics, and an infusion of disability material into current courses. Possible recommendations include certifications or sequences about disability studies available for undergraduate students. Graduate level training specific to disabilities across the lifespan, not solely in education, and with an emphasis on interdisciplinary training is also recommended.

University awareness and attitudes toward people with disabilities can create a culture of acceptance or negativity for students with disabilities (Bowman, 1987; Burgstahler, 1994; Mullins, Rossler, Schriener, Brown & Bellini, 1997). Interestingly, an overwhelming majority of undergraduates, graduate students and faculty members in this study report feelings of admiration for person with disabilities. While these results may be positive, it is possible that people with disabilities may not want to feel admired or glamorized because of their disability. Just as in any undergraduate students, graduate students and faculty feel pity and embarrassment when interacting with students with disabilities. This finding further enforces the need for increased social and daily interactions with students with disabilities. McCarthy and Campbell (1993) stated that attitudes toward people with disabilities are related to the amount of direct contact individuals have had with disabled people. A campus where half the students and faculty report no social interactions with individuals with disabilities outside of the classroom needs to re-focus their efforts on increasing social opportunities in order for students with disabilities to feel more welcomed by the campus community. These findings indicate that students and faculty would benefit from intensive disability integration, for example a disability awareness campaign aimed at students and faculty to increase interaction and understanding of disability.

Inclusion for students with disabilities at the postsecondary level is not guaranteed under federal laws of non-discrimination or equal opportunity. This paper highlights a trend that many students with disabilities are not being included in university activities. Few students and faculty in this study report having interactions with students and others with disabilities either in school, the workplace or social interactions. It is not surprising then that students and faculty feel awkwardness, embarrassment, or pity when interacting with persons with disabilities.

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# Authentic Inclusion: A Celebration of Exceptional Teachers and Student Identity A Phenomenological Self-Study

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## Research Articles

**Abstract:** Abstract: This phenomenological study examines the professional struggles of teachers with disabilities, the influence these teachers have on the identity formation of students with disabilities, as well as their effect on regular education students. When allowed to celebrate their differences, teachers with disabilities cultivate disability pride. Disability culture then flourishes while diversity is honored in an authentic, inclusive school setting.

**Key Words:** teachers with disabilities, identity formation, authentic inclusion

\*Editor's note: this article was anonymously peer reviewed.

an image of truth

children gravitate toward

what is real, like them

(entry from the author's reflective journal).

I am a teacher, and I am a person who stutters (PWS). At times I am completely fluent, but at other times, I stutter on almost every word. My stutter is usually situational; phone calls bring it out, as does reading aloud. Since my stuttering is inconsistent, it means that there are people in my life who never know that I stutter (e.g., the neighbor) and there are people in my life who only know me as a person who stutters (e.g., the telephone customer service agent at Wells Fargo).

In my classroom, I stutter on a daily basis and the students know and accept this different way of speaking. In fact, they enjoy trying on stuttering like a dress-up costume; they like to see how stuttering looks on them. Of course, it

is not the same as my stutter because they are choosing disfluency and I have less, and at times no, control over it. When students do this they are in no way teasing me. Instead, they are innocently fascinated – and dare I say intrigued – by this unique way of saying words. And believe me, I can spot teasing from a mile away. This may seem incredulous, and it certainly is unbelievable to most school administrators. To be sure, as I stutter through my introductory statements I have heard giggles and faint imitations. However, after this predictable preamble, I quickly begin to unveil my disability. Giving a short history of my childhood experience with stuttering clears the air and helps students empathize. I then demonstrate the types of stuttering and explain that it isn't catching nor does it mean it I am nervous, insecure, or crazy (that always gets some laughs). Then I open the floor for questions, of which there are always many, and the education begins. After this introductory lesson, I have never had classroom teasing occur. There may be out-of-class teasing, although in a school this small I would be likely to hear of it quickly. And yet, even if teasing did occur, it would present a wonderful opportunity to empathize with students who have experienced teasing as well. I no longer fear this form of intolerance; it is simply a sign that students are ready to begin their disability education. However, I have not always felt this way.

When I first began teaching five years ago, my goal was to hide stuttering, or pass as a fluent person. In truth, this "goal" was assigned to me in my teacher education program. During observed lessons, I received a lower grade because my stutter was interpreted as a sign of nervousness or insecurity. Since I wanted a good referral

for a future potential job, I worked diligently to hide my stutter at all times. When teaching, I would employ circumlocution, which is frequently used by PWS who are trying to pass as fluent. This avoidance strategy involves substituting fluent-prone words for the problematic stutter-prone words. While this technique sounds desirable, it actually promotes fear of certain sounds and words. In addition, circumlocution causes rambling as I mentally scramble to find a fluent replacement word – the only bonus is a broadened vocabulary.

In my efforts to pass, I would also rehearse lessons – to the point of videotaping them – checking for signs of stuttering. When that proved too time consuming, I tried speaking very quickly, so I could basically run my words together and avoid stuttering. Of course, this is not an effective way to teach, and is certainly not preferable for the English Language Learner (ELL) students. Because of these efforts to pass, which resulted in what I think was less effective teaching (albeit less stuttering), I scored well on my later observations. I obtained a good referral, noting I had much better scores on the fluent lessons compared to the lessons in which I stuttered.

I have experience teaching kindergarten through eighth grade students, and in all classes, I stuttered. In all the classes the students were, and continue to be, understanding, kind, and patient. I know this may seem surprising. Perhaps it is the way that I openly discuss my stuttering; perhaps it is my unapologetic demeanor. Ultimately, I think it is the fact that all students feel different in some way, so seeing a teacher who embraces her uniqueness is actually a cathartic process for them, a rush of relief that finally they have a teacher that is not “perfect.”

This being said, while students have proven to be accepting and even celebratory, parents, employers, and administrators still have a long way to come. One interviewer/principal said that her junior high class would “eat me alive.”

I have yet to have been eaten alive by students, but adults are another animal. It was more than challenging to complete interviews while stuttering due to the prejudices surrounding the disorder, yet in all my experience I have seen only positives come from it in the classroom. The only negative aspect of my disability is the stress encountered when I phase between my tolerant classroom and intolerant society. If I cannot get hired due to my disability, how will special needs students gain access to a powerful role model, a teacher who embodies diversity? How will regular education students learn to accept disability as a normal part of life? And how will schools prepare all students for the complex, diverse society that awaits them after graduation?

## The Context of the Study

In addition to teaching, I am also completing my Master's of Education in Special Education at the University of Alaska Southeast. This program requires the successful completion of a phenomenological self-study in which the author explores a phenomenon significant to his or her current teaching situation; this study is the product of that requirement. However, in the course of my research, it became clear that this project was no longer just an assignment. Instead, this study became highly relevant to my personal and professional journey as a teacher who stutters, a teacher with a disability.

For the past six years, I have been a multi-grade classroom teacher in rural Alaska. In my present classroom of 11 students, I have four students with special needs ranging from vision-related issues, to learning disabilities in reading and writing, to attention deficit/hyperactivity disorder (ADHD). This means that one third of my students are exceptional; their needs are unique and require adaptations.

My students and I learn together in a Yup'ik Eskimo village in Southwest Alaska. The elders of the village speak Yup'ik, which is the traditional language, but the children primarily

speaking English. Overall, the Yup'ik language in our village has been dying.

There are 57 students in our kindergarten through 12th grade school. Fifty-five students are Alaska Native and two are of European-American descent. Ninety-six percent of the students in our school (100% of the Alaska Native students) receive Title I free and reduced lunches. The two students who make up the non-Native student body do not receive free and reduced lunch.

This rural village has a population of 230. The median household income is \$16,250 with 40% of people living below the poverty level. The population is 94% Native. The school, the city, local businesses, and commercial fishing outfits employ most of the work force. There are 150 employable people and 59 available jobs. The community housing in the village does not have running water or plumbing; however, work is almost completed on a water system that would provide all Native housing with running water and flush toilets. Half of the teacher housing has tank water systems, but no plumbing (Alaska Department of Commerce, Community, & Economic Development, 2007).

Students with exceptionalities are included in all lessons and activities in my classroom; these children are not removed for isolated instruction. Diverse and distinctive, each child brings his or her special quality to my room. The differences these children bring makes my classroom stronger as a learning community.

### **Statement of Purpose**

One purpose of this phenomenological self-study was to explore my feelings and beliefs about the discrimination and challenges that I experience as a teacher who stutters. Another purpose of this self-study was to describe the effects that an inclusive classroom educator who is herself disabled has on her students.

### **Research Questions**

1. What are my beliefs about parents, administrators, and employers accepting, celebrating, and hiring teachers with disabilities?
2. What are my beliefs about how teachers with disabilities affect the identity, experiences, and attitudes of their students?
3. How do these beliefs guide and inform my classroom practices?

### **Review of the Literature**

#### **Selection Criteria**

The essential purpose of the literature review was to locate scholarly articles pertaining to teachers who stutter and/or teachers with disabilities and their effect on students' identity construction. Since few articles addressing this specific question exist, the literature review broadened to include issues surrounding this topic, such as discriminatory practices, identity construction, and the cultivation of disability culture. Ultimately, the 19 articles that were selected met the following criteria: (a) examined the attitudes and beliefs that parents, administrators, and teachers have about hiring teachers with disabilities; and/or (b) described how teachers with disabilities affect the identity, experiences, and attitudes of their students. These articles were published in professional journals related to the field of education between 1997 and 2007.

#### **Search Procedures**

I searched four databases that index articles related to the field of education to locate articles related to my research topic. These databases included: (a) Educational Research Information Clearing House (ERIC) (EBSCOhost); (b) Education Abstracts (OLC FirstSearch); (c) Educational Journals (Proquest Journals Collection); and (d) Professional Development Collection (EBSCOhost). I used the following search term combinations to conduct advanced searches

of each database: (“teachers with disabilities”); (“stuttering” AND “quality of life”); (“stuttering” AND “role models”); (“hidden disabilities” AND “employers”); (“teachers with special needs”); (“teachers with disabilities” AND “employers”); (“teachers with disabilities” AND “parents”); (“disability culture” AND “identity construction”); and (“stuttering” AND “advocacy”).

### **Emergent Themes from the Review of the Literature**

Nineteen articles met the selection criteria and were included in this review of the literature. A number of themes emerged from these articles. Thirteen articles (68%) addressed the fact that people with disabilities experience ableism and discrimination due to negative attitudes, lack of understanding, and false stereotypes. Nine articles (47%) stated that role models are important for people with disabilities. Seven articles (37%) acknowledged that accepting disabilities is an important part of understanding disability. Six articles (32%) noted that teachers with disabilities can develop critical, reflective, pedagogical thinking and aim to reach all students by maintaining high expectations. Six articles (32%) stated that speech, hearing, and other communication disorders can affect an individual’s career choices. Four articles (21%) examined student perceptions, noting that students viewed teachers with disabilities as effective educators and in some cases became their teacher’s advocates. Four articles (21%) focused on how identity construction and formation (both in and outside of school) forms the foundation for future self-concept, goals, values, and beliefs. Three articles (16%) explained how society commonly views people with disabilities as heroic super cripples, an identity that reduces personhood status and limits future choices. Two articles (11%) detailed the classroom as a powerful arena for social change. Table 1 illustrates the themes found in the literature.

## **Methods**

While completing the review of the literature, I participated in a number of self-reflection activities developed by the educator and researcher Valerie Janesick (2004) to generate data for this self-study. Since the literature review was constructed in conjunction with these self-reflection activities, research and reflection were enmeshed in an inextricable process. During a six-month period, I wrote haiku, created an autobiographical collage, constructed a YaYa box, and kept a reflective journal. I used a modified version of the Stevick-Collaizzi-Keen method described by Brown and Duke (2005) and McCarthy and Duke (2007) to organize the data into a series of word tables. The Stevick-Collaizzi-Keen method is a highly reductive method of data analysis frequently used by researchers working within the phenomenological tradition of qualitative inquiry to systematically distill essential concepts, issues, and themes from text (Creswell, 2007).

The Stevick-Collaizzi-Keen method adheres to the following systematic procedure: First, I identified “significant statements” in each article. For this study, these statements referred to those that (a) addressed general issues surrounding teachers with disabilities including but not limited to those that stutter, and/or (b) addressed general issues surrounding students with disabilities, (c) addressed the identity construction/self-esteem of students with disabilities; (d) addressed the importance of role models in identity construction, (e) addressed the intrinsic and/or extrinsic effects of discrimination, and/or (f) addressed the nature and/or development of disability pride and/or disability culture in all contexts.

Next, I developed a list of non-repetitive, non-overlapping (verbatim) significant statements with formulated meanings. These formulated meanings signify my analysis of each significant statement.

**Table 1. Themes in the Literature**

	Prevalence of Ableism in Schools	Importance of Role Models	Importance of Accepting Disabilities	Effective Practices of Teachers with Disabilities	Speech and Hearing Disorders and Career Choice	Positive Student Perception of Teachers with Disabilities	Importance of Identity Formation	Images of the Super-Disabled (or Super-Crip)	Classroom as Arena for Social Change
Altholz & Golensky, 2004	X	X	X		X		X		
Bramlett, Bothe, & Franic, 2006					X				
Daniels & Gabel, 2004	X	X	X		X		X		
Ferri, 2001	X	X	X	X		X			
Gabel, 2001	X		X	X		X	X	X	
Glen & Smith, 1998	X				X				
Griffith & Cooper, 2002	X	X							
Hahn, 1997	X								
Harrison & Lemke, 2000		X							



Hehir, 2002	X		X	X				X	
Holmberg, 2001	X			X		X			
Lehmann, Davies, & Laurin, 2000	X								
Longmore, 2000		X							
Mossman, 2002	X		X	X				X	X
Putnam, 2005	X	X	X	X	X				X
Roberson & Serwatka, 2000		X				X			
Roseman, 1999					X		X		
Scotch, 1998		X							
Wilson, Powney, Hall, & Davidson, 2005	X								

Finally, I grouped the formulated meanings from all 19 articles into theme clusters (or emergent themes). These “emergent themes” embody the essential concepts from the entire review of the literature.

## Findings

**Table 2.** Attitudes and Practices of Parents, Administrators, and Employers toward Teachers with Disabilities (generated from the review of the literature)

1. Discrimination Against Teachers With Disabilities
  - a. Teachers with disabilities experience discrimination from parents, administrators, and employers.
  - b. Some disabilities have gained acceptance, while others continue to experience repression.
  - c. Teachers with disabilities try to pass as nondisabled to gain equal rights for employment; this reinforces the power nondisabled society has over people with disabilities.
  - d. Teachers with disabilities should not have to “overcome” their disability in order to be employed.
2. Emotional Effects of Discrimination on People With Disabilities
  - a. Profound and disturbing feelings of powerlessness, hopelessness, frustration, shame, and fear result from discrimination.
  - b. Future choices and opportunities remain elusive for those with disabilities resulting in feelings of apathy and hopelessness.
3. Teachers with Disabilities as Highly Effective Educators
  - a. Teachers with disabilities have increased understanding, sensitivity, empathy, and

higher standards for students with disabilities.

- b. Teachers with disabilities use multiple modalities for instruction to accommodate their disability.
  - c. Teachers with disabilities respect alternative ways of learning and support differentiation.
4. Cultivation of Positive School Culture
    - a. Accepting and celebrating disabilities in schools would foster a powerful school culture.
    - b. Schools that honor teachers and students with disabilities cultivate advocacy skills essential for life outside the classroom.
  5. Purpose of Education
    - a. Most school mission statements center on the self-actualization of community-minded students who can affect change in society; this cannot be achieved without the development of a solid sense of self-construct and identity in all students.

**Table 3.** How Teachers with Disabilities Affect the Identity, Experiences, and Attitudes of Students (generated from the review of the literature)

1. Negative Concept of Identity in Students With Disabilities
  - a. Students with disabilities are given messages of disease, abnormality, shame, incompetence, and intolerance.
  - b. These messages foster self-hatred, decrease self-confidence, and a fractured self-concept/identity.
2. Promotion of the Disability Continuum and Disability Culture
  - a. Schools must encourage students to move from shame to pride on the disability continuum.

- b. Disability culture is a valid and definable culture.
  - c. As with any culture, schools must respect and provide opportunities to recognize, cultivate, and celebrate the culture of students with disabilities.
3. Teachers With Disabilities as Role Models for All Students
- a. Students relate to teachers who have disabilities.
  - b. Role models are vital to the identity formation of students with disabilities.
  - c. As schools move increasingly towards inclusion and full mainstreaming teachers with disabilities are the very example of what these students could aspire to become. If schools do not hire such teachers, then what is the point of inclusion?
4. Classroom as Pseudo-Society
- a. Our classrooms are the future of our society; they are the catalyst for fundamental changes in our world. The acceptance of teachers with disabilities in schools will transfer into the acceptance of people with disabilities in society.
- a. I am a model of a person with a disability who has a positive identity.
  - b. My students can look to me and see that they will find a place in society.
  - c. All people with disabilities should be allowed to exist as they are without feeling the need to change to fit the desired, or accepted, norm.
  - d. Through proud words and actions I communicate daily that my disability is a part of me and makes me who I am today.
3. The Effect of Disability on Instruction
- a. I use multiple intelligences for instructional delivery and honor numerous ways of knowing.
  - b. I have high expectations for all my students because I know they can meet standards even though they experience disability.
4. The Effect of Disability on Classroom Culture
- a. My classroom supports open-minded, honest inquiry about disabilities.
  - b. My classroom is a safe place to be who you are.
  - c. My students and I are partners in advocacy.

**Table 4.** How My Experience with Disability Has Affected My Classroom Practices (generated from self-reflection activities)

1. Self-Doubt
  - a. The discrimination I have faced from society has reinforced feelings of self-doubt and shame in my life.
  - b. I often questioned if I could be an effective educator because of my stuttering.
  - c. It is easy for me to separate my professional abilities from my disability, but it seems difficult for parents, administrators, and employers to do so.
2. Role Model of Positive Identity

## Discussion

The findings of this self-study suggest that teachers with disabilities are a vital part of honoring and cultivating disability culture in our schools. Many of these conclusions resonate with my own experience as a teacher with a disability and are instrumental to my personal journey as a disability advocate. Identity construction, which is partially based on culture, is crucial to the self-development of students with disabilities. Toward this end, schools must honor disability culture. Teachers with disabili-

ties, such as myself, are authentic examples of how disability and normality can coexist; we are excellent role models for all students. These teachers are usually highly qualified, capable, and maintain high standards, as they have had to work harder for what most people take for granted. Disabled and nondisabled students respond positively to such teachers and carry newfound perceptions into the world. The present cycle of discrimination must be eradicated. Employing teachers with disabilities is the fundamental catalyst for future societal change. Finally, the token acceptance of a few disabilities has not improved the situation for all teachers with disabilities, including teachers who stutter.

As a PWS, I have felt the shame, frustration, anger and ultimate despair Roseman (1999) states a teen who stutters felt when he “seriously contemplated suicide” (p. 16). For so long, failure and stuttering were synonymous to me. It is only recently that I have cautiously journeyed from shame to pride on the disability continuum. Yet still there are still times when, after stuttering outside of the classroom, I am caught off guard by the intolerance of the nondisabled society. Abject shame grips me, and I stumble two steps backward. Returning to the classrooms inspires hope after these dismal moments. My wish for all my students is that they would achieve a sense of pride in their disability culture and personal identity much earlier than I did.

If teachers with disabilities are not employed in our schools, then this dream will remain unrealized. When I read Griffith & Cooper (2001), I am resolutely reminded that their research finds, “Educators with disabilities are valuable to our schools. Their presence can influence the perceptions of coworkers and students as well as provide a role model for students to live their lives fully integrated into our society” (p.21). Unfortunately, most parents, administrators, and employers do not yet share their beliefs. In this phenomenological study, it has been my aim to destabilize the current educational em-

ployment system, which is so deeply rooted in institutionalized discrimination, and so inherently devastating to teachers and students, disabled and nondisabled alike, and ultimately society as a whole.

In my daily thoughts as a teacher, and as a person with a disability, I wrestle with the unjustness of the present system. My stammering speech doesn't innately narrow my dreams; my dreams are narrowed when employers see my disability and not me. My disability is not an inherent problem; the problem is the way I am discriminated against in society. My views are supported by Michalko (2002), who states, “We do not suffer the condition of our impairments as medicine and the rest of society would have it, we ‘suffer’ our society. We suffer what our society makes of our impairments, and this, according to the social model, is ‘oppressive’” (p. 54).

## Conclusion

I am a teacher who stutters, and yet my students understand and learn from me – yes, they even see me as an effective and capable educator. Most importantly, they trust and admire me. I want to be myself and be a teacher at the same time. I represent a normal form of human diversity I am a valuable role model for all students. I am even an asset, as Hahn (1997) states:

“Because of their experiences, persons with disabilities are in a unique position to acquire a resource that is not generally available to others. They may, in fact, be able to achieve a viewpoint and an approach to everyday problems that most people lack. Instead of regarding disability as a loss, therefore, it might actually be considered a gain – in experiences, perspectives, and opportunities for creativity...” (p. 36).

Why cannot parents, administrators, and employers see teachers with disabilities in this



light? We are real teachers, authentic people, and educators of equal worth.

Creswell (2007) noted qualitative researchers frequently conclude their studies with creative elements "that speak to the essence of the study and its inspiration to the researcher" (p. 188). I conclude this study with a reflective cartoon to literally illustrate and figuratively "illuminate," a pivotal theme that emerged from my self-study.

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# Poetry Talks Back to Psychiatry: Poetic Retellings of Psychiatric Experience in Venezuela

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## Research Articles

**Abstract:** The following paper explores three Venezuelan contemporary poets who wrote about their psychiatric experiences. Through their poems they “talk back” to a psychiatric language that medicalized their suffering and stripped their experiences of meaning. The parallels between their writings and psychiatric survivor literature are considered.

**Key Words:** poetry, psychiatry, survivor literature

\*Editor’s note: this article was anonymously peer reviewed.

Throughout history, poets have been studied as “psychological curiosities” (Blumenthal, 1995, p.4). Often they are ambivalently portrayed as sublime and profoundly flawed. The diagnoses most frequently attached to poets include: (1) psychological disturbance in general (Ludwig, 1992), (2) bipolar disorder (Jamison, 1993), (3) depression (Kaufman, 2005; Kaufman & Sexton, 2006), (4) personality disorders (Post, 1994), and (5) cognitive disorders (Thomas & Duke, 2007). It is fair to say that psychology and psychiatry have always been fascinated by artists and poets (Bokey & Walter, 2002; Killick & Schaverien, 1997). Research on the psychic processes, pathologies, and mental functioning of creative artists and poets abounds (Abberbach, 1989; Kaufman, 2005; Kaufman & Sexton, 2006; Thomas & Duke, 2007).

However, this fascination has not necessarily led to empathy or benevolence. As if poets were a somewhat different species, the romantic notion of the rebellious and extravagant Lord-Byron-type still colors many stereotypes. Freud (1908/1964), who was not only a confessed admirer of writers such as Cervantes and Goethe, but also sometimes wrote admiringly of poets,

said, “We lay men have always been curious to know... from what source that strange being, the creative writer, draws his material” (p. 143). He took amply from their works, as the name of concepts like the “Oedipus Complex” clearly shows, but also sometimes refers to poets with contempt. For example, in *The New Introductory Lectures to Psychoanalysis* (1932/1964) Freud writes, “But poets are irresponsible people and enjoy the privilege of such license” (p. 106). We get a profound sense of contradiction when examining what psychiatry and psychology have had to say about poets.

But have psychology and psychiatry heard what artists and poets have to say? When clinicians write and speak about artists, have we really heard those artists? Have we just appropriated their works and their words as Freud did? Have we psychiatrists and psychologists used language to expand and deepen artistic comprehension, or rather to tame, domesticate, and intellectualize all that is provocative and unsettling in art? I will focus on a very specific place where poetry and psychiatry have met, that is the world of psychiatric institutionalization and therapy. But I will do it through the poet’s, and not the mental health professional’s, words. I will look at three Venezuelan contemporary poets, who have drawn from their personal experiences as users of mental health institutions, and I will see how the works of these poets link to the testimonies of other psychiatric facility users.

### Methodological Considerations

This paper began about a year ago when I went to a reading by one of Venezuela’s more distinguished poets, Armando Rojas Guardia. I had read a little of his work and knew that he had been hospitalized a few years back in a

psychiatric ward where I did my training as a clinical psychologist. At the reading, he spoke openly about his crises and the time he spent hospitalized. He introduced the poem “La Desnudez del Loco” [The Nudity of the Madman] as a comment on that hospitalization experience. I did not know this poem beforehand, nor had I known that this was his chosen work for the public reading. To hear about a place where I had worked and studied years before, to go back through the words of the poet to a place that had been filled for me with the most intense and varied of experiences was incredibly moving and thought provoking.

I could relate to his experiences; they chronicled the details of life in a psychiatric ward. His poetry described the daily routines. No extravagant or contentious rendering of the experience was presented. What was compelling, though, was simply the description of how he had experienced it all. It spoke volumes about the subjective experience of being a psychiatric in-patient. It seemed important to return with this account to the place where I was trained, to open space in one of the many staff meetings where we discussed issues related to our practice. But I hesitated, how would this account be taken? Would it be heard? Or would it be dismissed as a curiosity at best, or rejected as the work of a man with a psychiatric disorder at worse. I do not know the answer to that question yet.

All of these considerations are central to methodological approach because they speak of the dilemmas of who is allowed to speak. Under what framework is something accepted as valid, truthful, and relevant, or not? What procedures and languages must ornament human experience to be included in our deliberations? Why is it that a mental exam, a set of lab results, the answers to a survey, or a short phrase taken from a diagnostic manual each seems to have more authority than a man’s poetic retelling of his experience?

Post-colonial methodology has pondered some of these issues and offered insights to how we can expand our research tools to give voice to those who are systematically deprived of it and are subjected to and by our professional gaze. The challenges that post-colonial research (Tuhiwai, 1999) has tried to address seem analogous in many ways to the efforts made by the psychiatric user movements.

For example, Tuhiwai (1999) writes about how research on indigenous peoples has, under the expressed intention of goodwill, probed, recollected, appropriated, and ultimately exploited the life experiences of other cultures. This research often romantically and idealistically simplifies or arrogantly dismisses the constructed “Other.” All of which leads to dehumanization, to the objectification of the other’s experience. Some of these impressions can be applied to much of the relationship between art and psychology and psychiatry. As Blumenthal’s (1995) historical revision of the *American Journal of Insanity* (AJI) of the nineteenth century shows, the words of writers were routinely followed by “or in medical terms” (p. 4).

Blumenthal (1995) also mentions how the written works of asylum inmates often voiced their complaints of the inhuman conditions they were subjected to and how these challenges were easily dismissed by the medical institution:

“Some wrote extensively about their own experiences as victims of mental disease, while others spilled considerable ink decrying the iron hand of their keepers, who wrongfully restrained their liberty. But whatever the patients’ purposes in addressing the President, family members, asylum officials, friends, the Governor, and Brigham himself (an author of the AJI) their writings were published in the AJI to communicate the nature and extent to which their minds were impaired by mental illness” (p. 11).

Tuhiwai (1999) considers the need to understand and criticize four concepts in order to develop post-colonial methodologies. She considers them to be: (1) imperialism, or the imposition of a set of methods and research activities that appropriate and simplifies the other while not considering the impact of these actions on their lives; (2) humanity, or the use of terminology that disqualifies the human experiences of those studied as uncivilized, irrational, or only “partially human”; (3) writing, or the telling of stories only through the researchers or colonialists’ eyes and language; and finally (4) theory, or the totalizing tendency of colonial rendering of life. Thus, post-colonial studies may complement disability studies as they both address the themes of power and subjugations as well as possibilities for resistance (Nack Ngue, 2007). Other authors have explored the relationship between post-colonial and disability studies (Parek, 2007). Sherry (2007) though, points out that it is necessary to watch out for the differences of the experience of colonialism and disability that cannot be conflated. Post-colonial studies, he contends, offers tools to analyze issues of power, agency, and resistance, but perhaps tends to ignore issues of embodiment.

Post-colonial methodology would be that which allows “talking back,” “writing back,” or “researching back.” The methodology challenges the simplified, dehumanized, and universal-totalized notions of life controlled by those who position themselves as the most qualified to speak and write: In this case, the discourse of mental health professionals.

Audre Lorde writes: “The master’s tools will never dismantle the master’s house” (as cited in Tuhiwai, 1999, p. 19). But poets have a very potent tool at their disposition to begin the process of writing and talking back at the languages and powers that have sometimes been more oppressive than healing. In a sense, the de-colonizing potentials of the poems to be explored in this paper speak for themselves, as the task has already been done by the authors. Writing an essay to

expand on the poems runs the risk of doing just what it criticizes: speaking for them. An analysis of the texts at the same time frames them and interprets them in a particular way that serves the author’s purpose.

I will state my purpose as clearly as possible. As a clinical and community psychologist, who has worked on issues relating the clinical with the social, and as a person who experienced as a student the wonders and the dramas of a psychiatric ward, I will link these poems and psychiatric users’ literature in a way that relays their words back to the academic and professional settings where their words are not always heard. I will also explore the links that allow us to reflect on the multifaceted experience of being a psychiatric patient.

The four main poems I will be drawing from were written by three contemporary Venezuelan poets. Armando Rojas Guardia, who was born in 1949, is considered one of the country’s main contemporary lyrical writers and in the 1980s was part of the poetry collective Tráfico. Among his many published works of poetry and essays are *El Dios de la Intemperie* (1985a), *Poemas de Quebrada de la Virgen* (1985b), *Antología Poética* (1993), and *El Esplendor y la Espera* (2000).

Hanni Ossott was born in Caracas in 1946. She worked for more than twenty years as a professor of literature at the Central University of Venezuela and published numerous books of poetry and literary criticism. She translated some of the works of Rainer María Rilke and Emily Dickinson into Spanish. Her poetry books include among others, *Hasta Que Llegue el Día y Huyan las Sombras* (1983), *Plegarias y Penumbbras* (1986), *El Reino Donde la Noche Se Abre* (1987), *Cielo, Tu Arco Grande* (1989), and *El Circo Roto* (1993). She died in 2002.

Martha Kornblith was born in Lima, Perú in 1959 and moved to Caracas at eleven years of age. She studied literature at the Universidad Central and was part of the poetry collective Eclesidra that was prominent in the 1990s in



Venezuela. She published *Oraciones para un Dios Ausente* in 1995 before committing suicide in 1997. Two other poetry books have been published posthumously: *El Perdedor Se Lo Lleva Todo* (1997a) and *Sesión de Endodoncia* (1997b).

### Relationship with the Psychiatric Establishment

The works of these three poets span a varied array of themes, but all three make explicit references to the poet's psychiatric experiences. From Rojas Guardia (2005), I analyze a text titled, "La Desnudez del Loco" [The Nudity of the Madman], which was first published in the national newspaper, *El Nacional*. As mentioned before, I heard Rojas Guardia commenting and reading the text at an open recital in March, 2007. The poem "Pills" is taken from Ossott's (1993) book *El Circo Roto* [*The Broken Circus*] and Kornblith's (1995) poems "Jesse Jones" and "Monseratte Clinic" were taken from *Oraciones para un Dios Ausente* [*Prayers for an Absent God*]. I have translated the four poems from Spanish and included Guardia's in both English and Spanish as an appendix of the paper.

The poets dedicate some of their texts to psychiatrists (in Ossott's case, "Pills" is dedicated to psychiatrists in general and other poems of that book are dedicated to Dr. José Luis Vethencourth) or psychotherapists (Jean Marc Tausik, in the case of Rojas Guardia), and in some cases refer to psychiatric institutions (Clínica Moseratte, in the case of Kornblith). As mentioned in the introduction, Rojas Guardia explicitly referred to his stay at the psychiatric ward of the Hospital Clínico Universitario at the public reading of the poem "La Desnudez del Loco." The details of their psychiatric treatments are unknown to me and can only be guessed from the text. These details are not the main concern since this paper attempts to listen to their experience of the psychiatric system and not produce an "objective" review, but it can be argued that the specific contexts may be relevant to fully understand these experiences. I will deal only with

what the poets have voluntarily shared through their writings or interviews.

### Suffering vs. Illness

All three poets, though specifically referring to the experiences in relation to psychiatric care, invoke references to personal breakdowns. For example, Ossott makes a note at the end of her poem that refers to the time and a place where her personal struggle with mental health problems began. The breakdowns involve elements of autonomy, health, identity, self-worth, interpersonal relations, and meaning. The significance of having a mental health issue serious enough to require hospitalization and/or psychiatric medication is enough to occupy a considerable space in these artists' work. Their poems address different aspects of the difficulties of these experiences. I will organize these into recurrent themes.

Anguish and suffering seem to be unavoidable aspects of these retellings. All three, in one way or another, refer to suffering rather than sickness. Ossott (1993) explicitly challenges the description of her situation as a sickness:

"Without a clue of the real sickness

The sickness is living

the only

The sickness is the body

and pills don't help too much" (lines 13-17)

Kornblith (1995) writes of fear, of loneliness, of hopelessness. The whole book is filled with resigned hopelessness. In other poems, she writes more specifically of rage. In the poem "Tell me Jesse Jones," she speaks to a fantasized therapist and asks, "Is my hate analyzable?" (line 2). Rojas Guardia (2005) on the other hand, refers to madness and fevered mental states, but rather than expressing it as suffering, emphasizes more the suffering that comes from the stigmatization, control, and exclusion subjected to those who access these rapturous states. His



poem is a rendering of life in a psychiatric ward, through the particular experience of having to take a shower at a specific hour with all the other patients:

“We went in groups to the bathroom, disempowered fraternity of bodies, dripping flesh, in the middle of the world – because our stay was a cosmic bad weather, the meridian and absolute orphanage:

To see yourself nude in front of others, who are also nude, returning to the solar solitude of being a body standing in front of the eyes of others’ scrutiny, without the well doing and covering shadow of shame:

Only naked like guilty Adam with the sudden consciousness of being nude under the panoptic desolation of day, right on the axis of twelve o’clock” (lines 11-21)

Through this image, he challenges psychiatric constraint, but also societal constraints and internalized guilt that are related presumably to his breakdown. He, like Ossott, searches for another meaning to the word sickness, different from a medical description. These texts experientially express and link with critical perspectives on the oppressive gaze of psychiatry and the medical model (Cooper, 1967; Foucault, 1965, 1973; Goffman, 1961).

All three authors have been formally seen by doctors and nurses (as referred to in their poems), thus they have been diagnosed. Psychiatric explanations have been used to render their experiences comprehensible. Probably some of these explanations have been given to them. There is no method to confirm this fact, but it is often standard practice to receive a diagnosis. Yet these formulations do not seem to suffice, they are not the main reference in their poems that try to express and give sense to their experiences. Their relationship with psychiatric language seems at best uncomfortable. They play with this language in their poems, transforming

it into something else. Rojas Guardia transmutes symptoms (e.g., hallucinations, delusions, depressions, phobias) into the “only precarious sheet” (line 109) with which the madman who ran off to follow Jesus is covered, thus undermining the medical language, and turning it into a cover for other mystical meanings, perhaps more helpful for the personal assimilation of the experience.

Kornblith’s approach is that of defiance. She appropriates psychiatric language and uses it ironically on occasion. To a fellow hospitalized patient who made empty promises of love she “showed him psychopathy” (line 50, “Montserrat Clinic”). In “Tell Me Jesse Jones,” of her doctor she asks, citing Barthes, “is my boredom my hysteria?” (line 14). Ossott (1993), on the other hand, produces a musical crescendo by listing the pills with which she presumably was being treated. The list produces an escalation of tension that could be likened to the frustrating repetition of taking pills which then contrasts with the question that is left in the air:

“one pill  
two pills  
three pills  
Dayamineral  
Lithium Carbonate  
Haldol  
Neubion  
Ornavit  
Rivotril 2 mg  
and the Doctor?” (lines 1-11)

### **Resistance to Psychiatric Confinement**

All of the texts deal primarily with the poets’ relationships to the psychiatric establishment. Texts vary in their emphases on different aspects of these experiences. But a few topics are shared among them all. The experience of confinement and of control is very present in

Rojas Guardia's and Kornblith's works. Both refer to walls, imposed schedules, the lack of privacy, and the control and supervision of even simple daily tasks (such as restrictions on the use of silverware and making patients eat with their hands). Both refer to the constant search for life outside the walls. The lacks of liberty and autonomy are stressed as painful aspects of psychiatric treatment. Rojas Guardia's poem is built around a patient's rebellious attempts to bathe alone at the hour he personally desired and not at the scheduled time when all patients were led forcefully. His rebelliousness is not well received by the nurses and leads to imprisonment. He is subjected to solitary confinement in the "dungeon" where tools of control are used to force patients to conform. He reveals the use of strategies that suit the staff's needs rather than provide any healing, therapeutic, or calming function. The imposition of these rules and restrictions conveys an experience of oppression and impersonal, dehumanized relationships with the nurses and the doctors: "All under the showers, one by one... we undressed in a hurry (the nurse invited us to do it this way)" (lines 2, 7).

Kornblith (1995) employs irony in "Montserrat Clinic" to expose the same restrictions:

"We were allowed  
to get drunk with water to forget  
what we were not.  
Because in the end  
everything had lost its taste" (lines 1-6)

In her case, these two verses skilfully tie in with other sufferings. The drabness of the circumstance of her hospitalization is underlined by her internal debates: "...what we were not." The despair of her personal shortcomings is intertwined with the difficult situation in the ward: "because in the end/ everything had lost its taste." The dehumanized feeling she conveys appears only as an extension of the already depressive state in which she fell.

Medicalization and medication, therefore, seem to compound the impression that their sufferings are not being listened to as a human experience, but devalued and dismissed as symptoms. "and the doctor?" (line 11) asks Ossott, who pictures him as someone detached and incapable of addressing the real sources of her suffering. In her poem "Montserrat Clinic," Kornblith refers to the patients' idle hours waiting for the doctors, trying to act like "we still existed." The need for others to offer support and meaning comes through clearly in this poem. The need to feel confirmation of existing before another's sight, of being taken into account by the other at the time of grief is part of the plight registered in these texts. In "Jesse Jones," Kornblith's rage at being controlled, given medical appointments, and "dosified" runs parallel with her desire to establish an emotional relationship with Jesse Jones. She looked for love in medical meetings and made desperate attempts to be received and heard. She looks him up in the phone directory, calls, then hangs up.

The continuous presence of doctors and nurses, who are aloof and impose their rules and interpretations, is a theme in all of the texts. The dehumanizing effects impact a psychiatric user's identity and moral standing, and have been documented by classical studies in the area such as Goffman's (1961) work and reappear in these poets' renderings. It is perhaps, the most poignant critique of psychiatry and clinical psychology—professions that are based on listening but that are incapable of listening to anything outside of their own jargon. Those who resist are forced to submit to power, as Kornblith (1995) writes of a fellow patient:

"There was a man  
he gave me Laing and Cooper  
and although he preached antipsychiatry  
he didn't survive the insult  
of the medical conjures" (lines 41-45)

The authors are also aware of and take from the already classical texts that have questioned psychiatric practice as the reference to Laing (1967) and Cooper (1967) exemplifies. Rojas Guardia makes veiled references to Foucault, as well as more explicit analogies to concentration camps.

This approach contrasts with moments where their cries were contained, when they found someone who was capable of hearing. The fact that Rojas Guardia and Ossott dedicate some of their texts to their psychotherapists is significant. Kornblith states that Clínica Monserratte was not bad, just good and bad. Solidarity and camaraderie with other patients appear as the most benevolent aspects of the hospitalization. Rojas Guardia (2005) identifies with a youngster who has been locked in solitary confinement. He finds in the youngster a universal link to all who have experienced states of madness. He constructs a unifying ethos that helps to resist stigmatization and offers dignified interpretations of these experiences:

“We were and are, like him, those fevered searchers of what we haven’t lost, the perpetually perplexed before the real, that to others is only unthinkable – a simple magnitude of custom – those who, thanks to a privileged suffering, see the world upside down, the collective from a fanatical periphery, at man with the virginal startle of amazement, at the whole spinning universe with the fear of being the first human in front of fire or the exclamation of an oceanic plain (we live on atavistic terrors that others hold back from, to be safe of the surprise of the horizon on the immobile Garden of Olives)” (lines 154-165)

Kornblith (1995) also finds a humane connection with fellow patients and is able to gain some solace. She also shares her “symptoms” with others and is able to interpret them in affirming terms:

“My friend and I spoke  
of dog concerts at night,  
of barks that we thought  
were calling us.  
We discovered that delusions  
were a way to hold on  
to the ledges.  
We orchestrated dances  
with music that didn’t sound.  
Except for the hours of fear  
it was also possible to laugh” (lines 56-66)

### Search for Meaning

All of the poems search for meaning outside the medical discourse. In many ways, the poets are deeply engaged in an effort to give shape and meaning to their mental anguish.

Rojas Guardia’s search for meaning is a constant in his poetry. He has been classified as a mystical poet and in interviews states the wish to be able to express his “poetic vision of the world” (Márquez, 2000). His poem is a mystical reinterpretation of his psychiatric hospitalization and the experience of being different. He takes freely from the Bible and from Shakespeare, searching for analogies and interpretative metaphors with which to rethink the experience of madness. The image of the young man running from the mob with only a sheet allows him to suggest numerous links to the pariah, the persecuted, and the condemned, that the experience of being subjected to the normalizing gaze of the medical establishment and the stigmatizing interpretation that society commonly makes of madness. Through this image of the mystical rapt, he is able to offer a different interpretation of his experience.

The struggle he presents is also the struggle with the shame of being different. Overboe (2007), from a disability studies perspective, has termed this shame the “normative shadows.”

That is the “feeling... that one is constantly being judged according to different criteria of normality” (p. 229). Guilt appears over and over again in his poem as one of the obstacles to overcome, a “scarring” of consciousness, the internalized “legislative” gaze before which he feels compelled to dress the “comfortable dresses of submission.” Overboe’s retelling of the hospitalization and his use of metaphors opens space for a multiple and mysterious reading of the experience instead of the medical, closed, and simplified version. It also offers a dignified interpretation of the harsh experience of maddening passions as well as stigmatization.

Ossott’s poetry has been defined as a constant exploration of the meaning of existence, sickness, identity, and the soul (Saraceni, 2003). In the poem “Pills,” Ossott not only reinterprets the medical reading of sickness, but also closes the text by stating that it was written based on her personal experiences that began on a particular date (1980). In the book where this poem appears, constant references to psychiatry and hospitalization are made, so it is clearly an attempt to reorganize those experiences. All of her writings are highly influenced by a personal search to comprehend her existence; access to her irrational experiences occupies an important part of it. In the essay, “Defence of My Poetry,” (1993) she writes:

“The poet then has to descend from the heights of the light of consciousness to that intermediate zone of dawn. There she will enjoy the feast that the gods have offered. Because a poet, no doubt about it, is a creature touched by the gods. But is also a creature in danger of succumbing. That’s why poetry is the practice of a ritual, a litany that can save the poet. Poetry is risk, because it’s soul. All poetry is apparently inconclusive, provisional, equivocal and sombre” (p. 1).

Ossott uses a plethora of gods to express her relation to the different dimensions of her experi-

ence. Kornblith also looks towards a very personal interpretation of spirituality for comfort. But for her, this comfort is ephemeral. On one hand she prayed to “a god that wasn’t mine,” presumably having to subject herself to a Catholic environment, in spite of being of Jewish origin. Kornblith’s spirituality does not seem to ultimately contain her experience. In interviews, she spoke of feeling essentially without roots (Arráiz Luca, 1994). Only literature or “words” seem to offer a sense of comfort and meaning to her. Interestingly, Kornblith (1995) relates attachments to figures of authority (e.g., her boss, the doctor) in “Tell Me Jesse Jones” to her search for “the word,” condensing both:

“You are the word:

The more it rejects me the more I search for it,  
when I find it, it may comfort or abuse me,

it stays for only an instant, and then goes with some other.

You are the word:

You stone me because I’m foul-mouthed,  
I take literary advantage of you.

I want to fuck you.” (lines 90-97)

The need to erotically engage the object of her attachments is fused with her need to find “the word,” perhaps the need to articulate her emptiness, sufferings, and lack, but also the need to be physically comforted. She seems to use eroticism to search for control of these relationships. Her constant, desperate search for connection and for “the word” appears in both texts. Poetry is the medium through which this search is conducted. In “Monserrat Clinic” she writes:

“For the wiser

poetry was a place

where to orchestrate our escape” (lines 38-40)

There are moments when her desperation finds containment through her writings and she's able to calm her angst:

"Since then  
God is someone  
that resurfaces in those scribbles" (lines  
90-92)

But unfortunately, that comfort was not always enough; her poetry cannot be read without the painful backdrop of her suicide.

### Relation with Survivor Literature

Survivor literature from the psychiatric user's movement, as well as other critical studies of psychiatric institutions (Goffman, 1961), allows us to draw many parallels with the words of Rojas Guardia, Ossott, and Kornblith and helps to amplify their work. Survivor literature refers to the first person accounts that have appeared from ex-patients, consumers, and psychiatric survivors. Such writing attempts to reclaim the rights of survivors to describe their own suffering and to narrate their own experiences of the psychiatric system (Adame, 2006). This literature has been supported by the psychiatric user's and the mental health consumer's movements. These movements have sought to give voice to psychiatric users and challenge oppressive practices.

Survivor literature helps to challenge professional discourse. As a practitioner, I have found this literature compelling and powerful in shifting the focus of the "therapeutic experience" that has been described in professional literature. Instead of focusing on theoretical and abstract considerations, it forces one to ponder the concrete; one must look straight at the human condition within the therapeutic enterprise. In this literature, the many daily, sometimes simple, inhumane practices that are veiled under seemingly well-intentioned cures are rendered visible. Thus, the limitations of the therapeutic discourse are challenged.

The testimonies of survivors often criticize and reject the coercive nature of many therapeutic settings. For example, they might address how the experience of hospitalization most often involves the loss of choice for a psychiatric user. The person's sense of agency is disavowed and his or her potential contribution to recovery is disdained (Romme & Escher, 2000). One survivor recalls that among her experiences of hospitalization there was one in particular that helped her to feel more empowered because by accident she came to literally hold the key to the ward:

"I did not really think that the nurses were going to lock me in against my will, but it was reassuring to know that I could get out if they did. I think it illustrates well a paradox of mental health care: the need for containment without imprisonment – a fine line" (Holloway, 1999, p. 51).

Even if some of the literature expresses the need to sometimes be in a containing surrounding with access to caregivers, the level of containment plays a crucial role in a patient's experience of autonomy or invalidation.

Like Rojas Guardia, poet Clay (1999) recalls the feeling of being scrutinized and controlled. When asking for a knife and a fork to eat her meal, she receives a large spoon instead. When she complained that she couldn't eat that way, the answer she received was, "Everybody else does... do you think you are something special?" (p. 20). Lack of privacy is also mentioned in the poem.

Perhaps the most repeated element in these testimonies is the disavowal of humanity imposed by the medical discourse (Adame & Knudson, 2007; Champ, 1999; Clay, 1999; Davies, 1999; Manos 1999). Medication plays a complex role in this equation, because even though some poets mention the calming benefit of some drugs, there are a series of complicated effects brought on by the "cure" (Perkins, 1999).



The first effect mentioned is the strong feeling of having lost control of one's body. This reaction is especially traumatic if the effects are not brought to the attention of the user and explained beforehand, as many testimonies report (Davies, 1999; Manos, 1999). Patients also complain about the tendency to consider pills the main source of treatment, rendering them passive in the process and offering only a biomedical explanation to their experiences. Through these medical procedures, the person's experience can be completely dismissed and therefore dehumanized, and medical staff can begin to relate to categories and symptoms instead of people (Romme & Escher, 2000). Davies' (1999) writing echoes Ossott's call to the doctor when she expresses:

"One night I instigated a role-play of our madness and we jumped on the beds and proclaimed 'This is an asylum and we're mad women'. We objectified our madness and made fun of it, also making a mockery of the staff who were so terrified of accepting it. The only interaction we had with nursing staff was through pills, food and ECT" (p. 108).

Or Clay (1999) who reports:

"Dr. Pacella would not talk with me about anything more profound than my eating and sleeping patterns, and our visits at West Hill never lasted more than ten minutes. Never once was I allowed to describe what had happened in my mind and heart or to express what it meant to me" (p. 24).

These limiting conversations coupled with detailed scrutiny and loss of freedom contribute to experiencing a psychological breakdown as a profound loss of dignity and self-worth. All poets report a shattering experience of self-doubt, where previous personal attainments were put into question, professional status was threatened, and perhaps worst of all, moral standing was also diminished. This is not to say that the

impact of an emotional breakdown can be simplistically attributed to medical attempts to treat it. But the difficult experience of the breakdown is compounded by the social response of stigmatization and dehumanization that medical practice sometimes perpetuates.

In this context, the process of giving meaning to the experience becomes central. Over and over again, survivor literature refers to trying to understand the breakdown, most of the time at odds with simplistic biomedical formulations. Framing it as pathology served to disavow aspects of the experience. In Adame and Knudson's (2007) analysis of four survivor testimonies, they write:

"The survivors interviewed rejected the notion that the problems in their lives and various experiences of altered consciousness were the result of a biochemical imbalance. Instead, they connected personal problems with political, societal, and existential ones, such as oppression, discrimination, unemployment, poverty and life's lack of meaning and purpose" (p. 19).

Similarly Barker, Campbell, and Davidson (1999), in their conclusion of the collection of survivor stories, mention how spirituality seems to come up again and again as a way of making sense and reorganizing one's sense of self in the midst of profound mental turmoil. This search for meaning and making sense of the experience outside of medical discourse is evidently present in the poems discussed here. Rojas Guardia's rendering in particular seems to fit with Adame and Knudson's (2007) notion that survivors acknowledged the suffering as, "An important part of their lives and identities and not something to recover from per se. Most of them felt that if they had anything to recover from, it was the mental health system" (p. 10).

In the process of integrating mental health difficulties, support is undoubtedly considered crucial by the sufferers, but only certain types of support: that which was considerate and not disempowering. Here is where strong bonds are sometimes developed among other people suffering from common ailments. Many psychiatric users mention the important role played by other in-patients during hospitalization or the supportive nature of user groups. This also comes up in the texts mentioned and I argue that the abstract community of poets serves this function in the works of Ossott, Kornblith, and Rojas Guardia, who frequently take from other poets who have also shared their mental health problems. Writing provides the opportunity for engaging with a wider community that can help to speak about and make sense of the experience.

Barker, Campbell, and Davidson (1999) quote the words of Brownbill, another service user, that summarize splendidly many of the needs these voices express:

“They tend to want quiet, comfort, nice surroundings, being close to family and friends, clear information, someone they can trust, somewhere where it is OK to scream, practical help and sometimes medication if necessary... So much of mental health care provision is imposed from the supposed well to the supposed sick. It is time we took our customers seriously. If we were running a shop with as much arrogance regarding knowing what people want, we would be out of business in no time at all” (p.183).

### The Voices of the Poets

I believe the texts of Rojas Guardia, Ossott, and Kornblith offer unique opportunities of “talking back” to a discourse community that, although fascinated by the products of poets, still seems reluctant to listen and take seriously what they have to say about the ex-

perience of clinical psychology and psychiatry. The eloquence of these writers helps to expose the dehumanizing aspects of clinical treatment and also offers room to reinterpret and rethink the particular challenges of living with mental health problems.

Their words are not right or wrong in any definitive sense. They are not written for science, but for art. They offer an opportunity to question, to wonder about, and to experience life in its most perplexing occasions. They also offer an opportunity to reflect on what we have come to label pathology and therapy. I contend that not only do these works strive to offer testimony to the dehumanizing aspects of psychiatric treatment, but perhaps more important still they challenge simplistic and comfortable notions about what we contend normality and health to be. These works offer the capacity to disturb, as in Rojas Guardia’s words referring to the disciple who undresses and follows Christ:

“Disturb the habits – even that of dressing as everyone else-, to exile himself from the common place where collective reason feeds to turn himself in- only with his subterranean cloak, rebellious axiom of the proscribed, to the condemned logic of the other side, the hidden face of the real seen and lived inversely, against the grain.

That is what being a disciple meant to him.

And it still does.” (lines 121-128)

Rojas Guardia, Ossott, and Kornblith’s words not only shed light on the psychiatric enterprise, but they go further to call into question and disturb many of the dominant, unquestioned views of what a good life is.

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## The Nudity of the Madman

By Armando Rojas Guardia

Translated by Manuel Llorens

To Jean-Marc Tauszik

And the Lord God called unto Adam, and said unto him, Where art thou? And he said, I heard thy voice in the garden, and I was afraid, because I was naked; and I hid myself. And he said, Who told thee that thou wast naked? (Gen 3, 9-11)

### 1

Bath time was at twelve

All under the shower, one by one

The walls: fading yellow

Midday's sun on the windows

We left the patio behind, the immobile trees and the rotund empire of the August light

We undressed in a hurry (the nurse invited us to do it this way).

Together and nude before the four faucets from where the ancestral therapy applicable in these cases flowed: cold water.

We went in groups to the bathroom, disempowered fraternity of bodies, dripping flesh, in the middle of the world – because our stay was a cosmic bad weather, the meridian and absolute orphanage:

To see yourself nude in front of others, who are also nude, returning to the solar solitude of being a body standing in front of the eyes of others' scrutiny, without the well doing and covering shadow of shame:

Only naked like guilty Adam with the sudden consciousness of being nude under the panoptic desolation of day, right on the axis of twelve o'clock.

Yes, the sun in the windows was also a coherent and vertical eye: the sight of God, omniscient, from which we desired to flee, the only escape to not feel the shame of being always seen nude, with pouring sweat.

And the water of the shower falls over the flagrant and shared nudity and does not lessen the burning of that live Eye stuck in the pulp of being man, that sun without eyelids shining on the skin soaked by the stream of a great liquid fire.

Our feet splashed in the puddles that the cracks on the floor helped to surface around them and a disgust flowers towards the mouth:

Nausea of corrupt water that we step on, of those viscous puddles, of the sticky humidity, the smell of urine, the dirty tiles, disgust of so much genital helplessness in the clear centre of the body while the paranoid stupor of the world continues bombarding with eyes and more eyes inside the totality of the heat.

We finally began to leave, one after the other.

The trees moved. August shone, precise, in the dense light that gravitated around the patio.

Lunch awaited (the food was taken with our hands: silverware could mean suicide attempts).

This jail ration on our fingers became another, embarrassed way of being perpetually watched – ridiculous now, retrieving a fistful of rice with the clumsiness of those who still haven't gotten used to eating this way-, at each bitten mouthful the nude panic of Adam at midday that in the bath was sensorial certainty, clairvoyance.

### 2

But he didn't want to bathe at the hour we all had to. He wanted to be beneath the shower at his own personal schedule, unforeseeable: in the morning or the afternoon, not at twelve. What motives led to this strange desire that automatically implied indiscipline, a

heterodoxy of habits violently breaking the imposed norm of the code?

Maybe it was the need, the urge to escape, on time and off time, from that burning Eye before which we were all nude, to refresh with the impetus of water that terrible fever that exposed our solitary shame to the gaze of others, the unique and multiple Eye examining there, in the heat, scrutinizing us, examining us. Maybe it was the call to feel permanently hygienic, clean from any corporeal contamination where to project the timely persecution of guilt, that of being essentially and not circumstantially dirty. Maybe he wanted to bathe alone, away from the promiscuous convergence that reunited the others around the stream, of that crowd where the whole private, intimate perception that the body has of itself was abolished and sacrificed to the mere animal fact of being not together but juxtaposed, like the horde and the herd. Or was it that the desire for a bath not subjected to regulations consisted in the need to install an individual space, oxygenatedly free –to be naked in front of the water also has a sense of physical freedom, plenitude- in which convention, that which is accustomed and institutionalized adjusts itself to the vivacious dictates of the body, and not it to them, penetrating in this manner in an unheard of independence and autonomy?

The nurse disliked this behaviour that broke the rules. Brandishing his right hand the iron that he used to stamp through the gesture of his authority among us, one morning he took the boy –nude, of course- from his personal bath and led him to the dungeon (because in this house there was a dungeon) and left him there for hours. I've always wondered what this guy felt in that stinking room, without any furniture in between the humid walls, sitting or laying on the gelid cement, looking at the unread clarity that amassed without grace in the crystals of the high skylight, the only possible contact with the sun that, outside,

feasted in the patio and with the morning breeze and the absurdly remote sky at that hour of the day. The prisoner was nude.

Another nudity, different now from the one sought to clean your own body in the holy water, under the shower, was now offered in that dungeon: that of being without cover in the gelid humidity and that of being excluded, being condemned.

### 3

A young man, wearing nothing but a linen garment, was following Jesus. When they seized him, he fled naked, leaving his garment behind. (Mark 14, 50-52)

We, nude, in the bathroom –the bathroom was the converging summary of all our life in that house and the kid nude in his prison were and still are that man that Mark infiltrates, surreptitiously in the Gethsemane of then and now.

Who was that youngster who followed Jesus with the lunar flesh covered only by the one cloth of blanket that night of sweat and blood, of unheard cries, of betrayal of the kiss, of torches and groups, tunics and swords, rumour of steps in the bushes, piled up shadows on the prowl, humiliation and arrest and, at the end, stubborn roosters at sunrise?

What unthinkable passion can guide someone to go out to the rejection and threat, under the universal indifference of the stars and only with a solitary sheet for clothes?

Was there not fever in the mind of the young man?

Didn't his presence here and his dress, obey a different consciousness from the ordinary, a vision of Jesus that did not fit into the official regime: the custom?

Mark writes, with precision, that he followed him.

He followed then Jesus as a disciple, as others did in his land, as we must now do one day after the other.

A disciple was, illuminated by a mental ardour that took him to expose himself to danger and disturb the habits – even that of dressing as everyone else-, to exile himself from the common place where collective reason feeds to turn himself in- only with his subterranean cloak, rebellious axiom of the proscribed, to the condemned logic of the other side, the hidden face of the real seen and lived inversely, against the grain.

That is what being a disciple meant to him.

And it still does.

He escaped in the nude. Only nude could he escape the mass avid of blood, the insomniac troop, the confusion of voices and shouting, the pushes, the insults, escape from the societal hour of the law looking for a transgressor, the prisoner of always.

His nudity was momentary liberty to escape from the gregarious plot that needed an expiatory victim, to the eternal signalled of not being like everyone else: the different one.

But he didn't flee, not from the Passion.

He was completely – his presence in the story confirms it- inscribed in the tragedy that Thursday night designed for any disciple of the condemned: I imagine him walking now nude at first at the edge of the nettle that in the field lacerated his skin, then in the streets before the unanimous amazement of the neighbours, the passer-bys, damming perhaps his lack of shame, asking where was he arriving from at this hour without clothes.

His nudity was observed, scrutinized with objecting curiosity, meticulous.

What did he feel, nude, arriving at his room and to think of the house of Caifas, filled with people?

Maybe he too heard the rooster's call in the nubile shame of the dawn.

We all were and are the evangelical youngster:

Twelve o'clock under the shower and the morning in the dungeon make up an only frozen night, a shared agonic Gethsemane.

We were and are, like him, those fevered searchers of what we haven't lost, the perpetually perplexed before the real, that to others is only unthinkable – a simple magnitude of custom- those who, thanks to a privileged suffering, see the world upside down, the collective from a fanatical periphery, at man with the virginal startle of amazement, at the whole spinning universe with the fear of being the first human in front of fire or the exclamation of an oceanic plain (we live on atavistic terrors that others hold back from, to be safe of the surprise of the horizon on the immobile Garden of Olives).

No, it has never been easy for us to live.

Filled with our metaphysical stupor, our dissonance before the Law, our vocational dissent, our tangential oblique ways of being members of the species, our metaphorical following- covered by only a precarious sheet of the hallucinations, delusions, depressions, phobias, the mania.

That who was spoken of in these terms:

He hath a devil, and is mad; why hear ye him? (John, 10,20) and crueller still: When his relatives heard of this they set out to seize him, for they said, "He is out of his mind." (Mark 3, 21) – Madness as metaphor and image of the following of Jesus:

For the wisdom of this world is foolishness to God (1, Cor 3, 19) An unconscious way of following him that can become voluntary if one becomes conscious of the grace that receiving this sickness is, as an invitation to live

another way, with fear and tremor before the miracle of existing every day, under the sky.

And nude. We are nude, as the youngster, in the bathroom or at the middle of the dungeon escaped, naked of the shared use of social reason that demands victims and nails, naked, on the wood he who, because of his difference carries all the guilt of those that are like the common man, the identical form.

Madness is the nudity through which we escape from the routine of this legislative reason that produces, marginalizing us, the pariahs, the stained, the impure –T'was crazy King Lear who, because of him being it, could pronounce confidently before Edgar from the solitary majesty of his delusion: None does offend, none, I say, none, I'll able 'em. Madness as the acquitting innocence that undresses men of their faults.

4

But the freeing nudity knows well the paradox of also being that other, our own nudity now perceived as the stigma of being examined by the eyes of others, by the pupil of the Other, in front of who that same nudity leaves us unprotected, observed by the alien gaze that scars the consciousness of self, to its marrow.

And the naked man who didn't care anymore about the comfortable dresses of submission now seeks desperately, to be dressed by the approval of that gaze that scratches, enslaving him.

Both nudities are intertwined in the body of the only madman.

And I ask my self if health, the only possible and desired healing, which doesn't supply or offer sanatoriums with their multitude of showers of cold water and dungeons for the dissident desire (While I was there I thought of Auschwitz, of Dachau?) consists of breaking the inextricable plot that confuses one with the other:

the nude freedom of Adam in the Garden and that same nudity already ashamed.

## La desnudez del loco

Armando Rojas Guardia

A Jean-Marc Tauszik

(...) El Señor Dios llamó al hombre -¿Dónde estás? Él contestó: -Te oí en el jardín, me entró miedo porque estaba desnudo (...) Y el Señor Dios le replicó: -Y ¿quién te ha dicho que estabas desnudo? (Gen 3, 9-11)

1

La hora de bañarse era a las doce.

Bajo la ducha todos, uno a uno.

Las paredes: amarillentas, desteñidas.

El sol del mediodía en las ventanas.

Atrás dejábamos el patio, los árboles inmóviles y el rotundo imperio de la luz de agosto.

Nos desvestíamos con prisa (El enfermero conminaba a hacerlo de ese modo).

Juntos y desnudos ante los cuatro grifos de los que brotaba la ancestral terapia aplicable en estos casos: agua fría.

Llegábamos en grupos hasta el baño, desamparada fraternidad de cuerpos, goteantes carnes, en la mitad del mundo -porque estar allí era una cósmica intemperie, la orfandad meridiana y absoluta:

verse a sí mismo, desnudo ante los otros, desnudos también ellos, devolviéndonos a la solar ingrimitud de ser un cuerpo parado allí frente a los ojos del escrutinio ajeno, sin la sombra bienhechora y cobijante del pudor:

sólo desnudo como el Adán culpable con la conciencia súbita de estarlo en la desolación panóptica del día, justo en el eje de las doce en punto.

Sí, el sol en las ventanas también era un ojo coherente y vertical:

la mirada de Dios, omnividente, de la que deseábamos huir, sólo escapar para no sentir la vergüenza de ser vistos siempre desnudos, con el sudor manante.

Y el agua de la ducha va cayendo sobre la desnudez flagrante y compartida y no aminora el ardor de ese Ojo vivo clavado en la pulpa de ser hombre, ese sol sin párpados brillando sobre la piel empapada por el chorro de un gran incendio líquido.

Nuestros pies chapotean en los pozos que las grietas del piso hacen aflorar en torno a ellos y un asco en flor asciende hasta la boca:

náusea del agua corrompida que pisamos, de esos viscosos charcos, de la humedad pringosa, del olor a orina, de las losas sucias, asco de tanto desamparo genital en el centro nítido del cuerpo mientras el paranoico estupor del mundo permanece acribillado de ojos y más ojos dentro de la totalidad de la canícula.

Íbamos por fin saliendo, unos tras otros.

Cabeceaban los árboles. Agosto refulgía, preciso, en la luz densa que gravitaba alrededor del patio.

El almuerzo aguardaba (la comida era tomada con las manos: los cubiertos podían significar intentos de suicidio).

Y esa ración de cárcel en los dedos venía a ser otra manera, avergonzada, de ser siempre observados -ahora ridículos, asiendo un puñado de arroz con la torpeza del que no se habitúa a comerlo de ese modo-, en cada bocado masticando el pánico desnudo de Adán a mediodía que en el baño fue certeza sensorial, clarividencia.

## 2

Pero él no quería bañarse a la hora en que todos debíamos hacerlo. Deseaba estar bajo la ducha

de acuerdo a un horario personal, imprevisible: por la mañana o por la tarde, no a las doce. ¿Cuáles motivos conducían a ese raro deseo que implicaba automáticamente indisciplina, una heterodoxia de hábitos violentando el código impuesto, normativo?

Quizá era la necesidad, la urgencia de escapar, a tiempo y a destiempo, de aquel Ojo calcinante ante el cual todos estábamos desnudos, de refrescar con el ímpetu del agua esa fiebre atroz que exponía nuestra íngrima vergüenza a la mirada de los otros, del Otro único y múltiple oteándonos allí, en caliente, escudriñándonos, examinándonos. Acaso era el llamado a sentirse permanentemente higiénico, limpio de cualquier contaminación corporal en la cual se proyectara la puntual acechanza de la culpa, la de ser -y no sólo la de estar sucio. Tal vez quería bañarse a solas, alejado de la promiscua convergencia que nos reunía a los demás alrededor del chorro, de aquel hacinamiento donde toda la privada, la íntima percepción que tiene el cuerpo de sí mismo era abolida y sacrificada al mero hecho animal de estar no ya juntos sino yuxtapuestos como en la horda y el rebaño. ¿O ese anhelo de baño no sujeto a reglamentos consistía en el ansia de instaurar un espacio individual, oxigenadamente libre -estar desnudo en medio del agua guarda también un sentido de libertad física, plena- dentro del cual la convención, lo estatuido y la costumbre se amoldaran a los dictados vivaces del cuerpo, y no éstos a ellos, penetrando, así, en una autonomía, en una independencia insólitas?

Al enfermero le disgustó esa conducta al margen de las reglas. Blandiendo con la mano derecha el rejo que utilizaba para rubricar gestualmente su autoridad entre nosotros, una mañana sacó al muchacho -desnudo, por supuesto- de su baño personal y lo condujo al calabozo (porque había en ese caserón un calabozo) y lo encerró allí durante horas. Siempre me he preguntado lo que ese compañero sentiría en aquella habitación



hedionda, sin un mueble, en medio de los muros húmedos, sentado o acostado sobre el cemento helado, mirando la desleída claridad que se apelmazaba sin gracia en los cristales de un alto tragaluz, único contacto posible con el sol que, afuera, festejaba al patio, y con el viento matutino, y con el cielo absurdamente remoto a esa hora del día. Estaba desnudo el prisionero.

Otra desnudez, distinta a la buscada para lavar el propio cuerpo en el agua lustral, bajo la ducha, le era ahora ofrecida dentro de aquel calabozo: la de estar sin abrigo en la gélida humedad, y la de estar excluido, siendo un réprobo.

### 3

Un joven lo iba siguiendo, cubierto tan sólo con una sábana. Le echaron mano, pero él, soltando la sábana, se escapó desnudo. (Mc 14, 50-52)

Nosotros, desnudos, en el baño -el baño era el resumen convergente de toda nuestra vida en esa casay el muchacho desnudo en su prisión éramos y aún somos aquel hombre que Marcos infiltra, subrepticio, en el Getsemaní de entonces y de ahora.

¿Quién era aquel joven que seguía a Jesús con la carne lunar cubierta apenas por el único ropaje de una sábana en esa noche de sudor de sangre, de inescuchada súplica, de la traición del beso, de antorchas y grupos, túnicas y espadas, rumor de pasos entre la maleza, amontonadas sombras al acecho, humillación y arresto y, al final, los tercos gallos del amanecer?

¿Qué pasión inaudita puede conducir a alguien a salir hacia el oprobio y la amenaza, bajo la indiferencia universal de las estrellas con sólo una íngrima sábana por ropa?

¿No había fiebre en la mente de ese joven?

¿No obedecía su presencia allí, y su atavío, a una conciencia distinta a la ordinaria, a

una visión de Jesús que no cabía en el tácito régimen oficial: lo acostumbrado?

Marcos señala, con exactitud, que lo seguía.

Seguía, pues, a Jesús como un discípulo, como lo hacían algunos en su patria, como hay que hacerlo ahora, un día tras otro.

Un discípulo era, iluminado por un ardor mental que lo llevaba a exponerse al peligro, a trastocar los hábitos -incluso el de vestirse como todos-, a autoexiliarse del lugar común del que la razón colectiva se alimenta para entregarse -únicamente con su sábanaal subterráneo, rebelde axioma del Proscrito, a la réproba lógica del envés, la cara oculta de lo real visto y vivido a la inversa, a contrapelo.

Eso significaba, para él, ser un discípulo.

Y eso significa todavía.

Se escapó desnudo. Sólo desnudo podía huir de la muchedumbre ávida de sangre, la soldadesca insomne, la confusión de voces y de gritos, los empujones, los insultos, huir de la hora societaria de la ley buscando al Transgresor, al Reo de siempre.

Su desnudez fue momentánea libertad para escapar de la gregaria trama que necesitaba a su víctima expiatoria, al señalado eterno con la culpa de no ser como todos: el distinto.

Pero no huía, no, de la Pasión.

Estaba todo él -su presencia en el relato lo confirma- inscrito en la tragedia que la noche del jueves diseñaba para cualquier discípulo del Réprobo:

lo imagino andando ahora desnudo primero al ras de las ortigas que en el monte le laceraban la piel, luego en las calles ante el unánime asombro de vecinos, transeúntes, maldiciendo acaso su impudicia, preguntándose de dónde vendría sin ropas a esas horas.

Su desnudez era observada, escudriñada con curiosidad objetante, minuciosa.

¿Qué sintió, desnudo, al llegar a su cuarto y pensar en la casa de Caifás, llena de gente?

Quizá escuchó él también el canto de los gallos en la vergüenza núbil de la aurora.

Nosotros todos éramos y somos aquel evangélico muchacho:

las doce del día bajo la regadera y la mañana en el calabozo configuran una única noche detenida, un mismo Getsemaní agónico.

Éramos y somos, como él, aquellos afiebrados buscadores de lo que no se nos ha perdido, los perpetuos perplejos ante lo real, que para los demás es únicamente sólito -una simple magnitud de la costumbre-, los que, merced a un privilegio padeciente, ven al mundo al revés, al colectivo desde una periferia contumaz, al hombre con el virgen sobresalto del asombro, al universo entero girando en el pavor del primer ser humano frente al fuego o la exclamación de una llanura oceánica (vivimos de atávicos terrores que los otros se escamotean a sí mismos, para estar a salvo de la estupefacción del firmamento sobre el inmóvil Jardín de los Olivos).

No, nunca fue fácil vivir para nosotros.

Llenos de nuestro metafísico estupor, nuestra disonancia ante la Ley, nuestra subversión vocacional, nuestra manera tangencial, oblicua, de ser miembros de la especie, nuestro seguimiento metafórico -cubiertos por una única sábana precaria en las alucinaciones, el delirio, la depresión, las fobias, la maníade Aquél de quien se habló de esta manera:

está loco de atar, ¿por qué lo escuchan? (Jn 10, 20) y más cruelmente todavía:

sus parientes fueron a echarle mano, porque se decía que no estaba en sus cabales (Mc 3, 21) -La locura como metáfora e imagen del seguimiento de Jesús:

pues la sabiduría de este mundo es locura para Dios (1 Cor 3, 19) Un modo inconsciente de seguirlo que puede convertirse en voluntario si uno toma conciencia de la gracia que ha sido recibir la enfermedad como invitación a vivir de otra manera, con temor y temblor ante el milagro de existir todos los días, bajo el cielo.

Y desnudos. Estamos desnudos, como el joven, en el baño o en mitad del calabozo escapados, desnudos del uso compartido de la razón social que exige víctimas y clava, desnudo, en el madero al que por ser diferente carga todas las culpas de los que son iguales al rasero común, a la horma idéntica.

La locura es aquella desnudez a través de la cual nos escapamos de la cotidianidad de esa razón legislativa que fabrica, marginándolos, a los parias, los manchados, los impuros -Fue el loco Rey Lear quien, por serlo, pudo sentenciar ante un Edgar confidente desde la desolada majestad de su delirio:

Nadie es culpable, nadie, digo que nadie: yo seré su fiador La locura como inocencia absolutoria que desviste a los hombres de sus culpas.

4

Pero esa desnudez libérrima conoce la paradoja de ser también la otra, la propia desnudez ya percibida como maldición al ser examinada por los ojos de los otros, por la pupila del Otro frente a la cual nos desprotege ese mismo estar desnudos, observados por la visión ajena que se lla en la conciencia de sí, hasta su médula.

Y el desnudo al que ya no le importaba el cómodo ropaje de la sujeción busca ahora, desesperadamente, ser vestido por la aprobación de esa mirada que lo escarba, esclavizándolo.

Las dos desnudeces se entrelazan dentro del cuerpo único del loco.

Y me pregunto si acaso la salud, la sola  
curación posible y deseable que no aportan ni  
aprontan sanatorios con sus multitudinarios  
baños de agua fría y calabozos para el deseo  
disidente (¿Pensé, estando allí, en Auschwitz,  
en Dachau?) consiste en romper la trama  
inextricable que confunde la una con la otra:

la libertad desnuda de Adán en el Jardín y esa  
misma desnudez ya avergonzada.

{ Armando Rojas Guardia, *Papel Literario, El  
Nacional*, 5 Febrero, 2005



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# Pioneering Access for Those with Environmental Sensitivities: An Interview with Susan Molloy

**Lauren G. Sledd, Sahisna Suwal, & Pamela Reed Gibson**  
**James Madison University**

## Research Articles

**Abstract:** Chemical and electrical sensitivities are often invisible disabilities. Those with electrical hypersensitivity experience symptoms that result from exposure to a variety of sources of electromagnetic fields and radiation, including electrical appliances, florescent lights, computers, and cell phones and their towers. Most research has been conducted in the area of chemical sensitivity; persons with chemical sensitivities experience a wide range of negative disabling reactions to common chemicals such as fragrances, pesticides, paints, cleaners, and exhaust fumes. Recent findings indicate that chemical sensitivity is found world-wide and crosses lines of gender, race, and age. Susan Molloy has been advocating for persons with environmental sensitivities since 1983. In this interview, Lauren Sledd put questions to Molloy to illuminate the history of her pioneering advocacy.

**Key Words:** environmental sensitivities, exposure, chemical sensitivity

### Introduction

Chemical and electrical sensitivities are “invisible” disabilities often ignored by industrial culture and its institutions, including mainstream service providers. Persons with chemical sensitivities (often called “multiple chemical sensitivity” or MCS) experience a wide range of negative disabling reactions to common chemicals such as fragrances, pesticides, paints, cleaners, and exhaust fumes. These reactions can affect any bodily system, and common symptoms include tiredness/lethargy, difficulty concentrating, muscle aches, memory difficulties and long-term fatigue (Gibson & Rice, 2009). Those with electrical hypersensitivity experience symptoms from exposure to a variety of sources of electromagnetic fields and radiation, including electri-

cal appliances, florescent lights, computers, and cell phones and their towers.

More is known regarding chemical sensitivity than electrical hypersensitivity at this time. For example, it is believed that people with chemical sensitivities first sensitize to one chemical, which then causes symptoms upon subsequent exposures. The sensitivity then tends to spread to other similar and subsequently dissimilar chemicals, until the person is faced with a need to avoid a large number of common settings (Gibson, 2002). Because of the incapacitating health effects of exposures, people with disabling sensitivities thus lack access to crucial resources including housing, employment, medical care, education, rehabilitation programs, and even homeless and domestic violence shelters. Consequently numerous stressors, including health emergencies and personal violence, may go unacknowledged in this population.

Prevalence studies suggest that chemical sensitivity is a worldwide and not uncommon disability. For example, Caress and Steinemann (2003) found in a U.S. household population study that 12.6% of respondents reported being sensitive to chemicals. In the Netherlands, 27% of 6,000 people reported experiencing multiple symptoms from common chemicals and 19% had made life adjustments to compensate (Berg, Linnegarg, Dirksen, & Elberling, 2008). Likewise, 15.6% of Swedish teenagers reported being “bothered by strong odors” and 3.6% had made life changes as a result (Andersson, Johansson, Millqvist, Nordin, & Bende, 2008). And in Germany, 32% of persons report that chemicals cause them symptoms (Hausteiner, Bornschein, Hansen, Zilker, & Förstl, 2005). Chemical sensitivity seems to cross lines of race, gender, and age, with severe life impacts for substantial

numbers of people. For example, job loss due to chemical sensitivity resulted in 1.8% of Caress and Steinemann's U.S. sample.

Susan Molloy has been advocating for persons with environmental sensitivities since 1983. Part of her attention has focused on gaining recognition of this problem by the Centers for Independent Living (CILs), nonprofit corporations that have been established in the U.S. and other countries to provide accommodations and services for persons with disabilities. The centers exist in the United States, United Kingdom, Australia, Canada, and Japan, and have been heralded as grass roots agencies run by and for people with disabilities. CILs vary in size and budget, but all are mandated to provide information and referral, independent living skills training, advocacy, and peer counseling to consumers with disabilities.

Members of the James Madison University MCS Research Team (Lauren G. Sledd, Sahisna Suwal, & Pamela Reed Gibson) were interested in Molloy's efforts to gain access to CILs for persons with sensitivities and crafted questions to explore these efforts. Lauren Sledd put the questions to Molloy to highlight the history of her pioneering advocacy. Susan's own survival challenges are examples of the difficulties faced by persons with environmental sensitivities.

## Interview

Sledd: When did you decide to go to the Centers for Independent Living and advocate for persons with chemical and electrical sensitivity disabilities, and what was your first experience with an Independent Living Center?

Molloy: I'd never heard of an ILC, nor had I heard of the disability that within one day, in summer 1981, took over my life. After getting hit hard with chemical and electrical sensitivities, the barriers to my participation in society were blatantly, immediately apparent. I couldn't go into offices or stores, or travel in a car or on the bus. When I walked down

the street, I felt a huge weight that seemed to come from the overhead power lines. I lived in downtown San Francisco and something painful kept coming at me from Sutro Tower. Within weeks, I was wearing the same lavender cotton blouse and beige pants day after day even as they became filthy. It hurt too much to touch freshly laundered clothes.

None of this made sense to me and there was no one to talk with about it.

I was going through a wrenching process, being morphed into a sick, disabled, homeless person. It was nearly impossible to rest anywhere. I had to be ready to get out...fast...from any place I lived or stayed in case something bad floated in on the air. I slept on a friend's back porch. I stayed with family. I stayed any place I could find where it seemed like I might not get hurt by whatever it was that floated in the air.

My possessions – household furnishings and clothes, my cat, nearly everything was soon given away or traded to friends, or appropriated if not outright stolen by strangers. I had never heard of "Environmental Illness," the chemical and electrical sensitivities, when I got hit.

Sledd: So did you not know at this point why everything hurt?

Molloy: The first night that I got sick with anaphylaxis, two friends took me to the emergency room. The E.R. doc used Atropine, Benadryl, and epinephrine to get me through the night. He said, next morning, that I was having an allergic reaction that had nearly killed me, and might have more. Several people in my family had serious sensitivities and allergies, but I'd always thought they were pathetic and effete. I assured him that I didn't have allergies.

Following repeated horrifying reactions to food, electricity, mold, and chemical exposures over the next several weeks, the possibility of some sort of allergy began to seem worth



exploring, or at least nothing else did. It seemed a reasonable step to check out this theory at a hospital. University of California Medical Center was a few blocks from the apartment where I was staying, so I made an appointment.

Sledd: How was it at the hospital?

Molloy: Then as now, medical facilities presented a number of threats. Diesel ambulances idle at the E.R. door, cleaning and maintenance chemicals, insecticide, fluorescent lights, carbonless copy paper forms, new synthetic carpet and furniture, and unshielded electrical devices present barriers throughout. In those days, patients and families smoked in hospital hallways, doorways, restrooms, and waiting rooms. It felt risky to entrust myself to anyone who'd make me fight through all the problems the hospital presented, but what were the options? So I did it. The conventional allergists and conventional tests – eventually at least they pointed toward some changes I could make in my diet. There was no help for the other reactions though.

Sledd: Yeah, I bet.

Molloy: Within the following weeks I became increasingly sensitized and threatened by every exposure, so figured I'd approach the Social Security system for help. I knew that sometimes a person who was very ill could apply for a monthly check in order to survive a calamity until back on their feet again and back at work. With no more idea about it than that, I called the Social Security office in San Francisco and said I was having a bad health problem, I didn't know what to call it, and it didn't seem to be getting any better. I asked to talk with someone who could help me plan what to do.

The clerk explained that I'd have to visit the office and sit in the waiting room like everybody else. I explained that there seemed not to be a way I could leave the house without

risking anaphylaxis again. Besides I'd seen the location of the Social Security office before, and there were always men smoking along the sidewalks around the doors.

As it turned out, I was unable to apply for two more years because I wasn't able to go to their office, and they refused to consider provisions such as interviewing me by telephone, coming outdoors to meet me, doing a home visit, or making any other provision. That seemed shortsighted and arbitrary to me, but I didn't yet see things in a civil or legal rights context.

The next year, I moved north to the country around Arcata, where I'd grown up. The air was better and the electrical exposures weren't so bad. I was glad to be near my family, no matter how they interpreted what had gone wrong for me.

One day I was walking along the pier by the bay, and noticed a little office with big windows facing the street. On the door there was a sign saying "Humboldt Access Project." People with disabilities were rolling around, walking around inside that office. I tapped on the glass and said I needed help. The director, Ben Harville, came to open the door, holding a lit a cigarette. He had no idea that he could kill me with that thing. I stayed outside, backing away. I gave Ben a description of the kinds of places I needed to go and what happened when I tried. I told him things had become like this only recently after years of having been a relatively "normal" person. I wanted him to tell me if what was going on with me had anything to do with access, if his agency helped people get access. He gave me some literature about the Independent Living principles, pamphlets and things, and invited me to come back, to the extent that it was possible, whenever I wanted to.

I did go back. I felt less stigmatized there than other places, even though I couldn't go inside. Over time, I learned the language and something about disability law and etiquette,

and how the ILCs choose what projects to do with funding they receive from the federal government. It had come to seem like a good thing to me, to work for inclusion within the IL movement. I liked the ILC people, and they used some concepts I thought might help to protect people like me. I learned a lot out on their sidewalk over the next few months.

Sledd: The first place you went to—you were going to for help? And they didn't understand?

Molloy: They didn't. Later, we realized that there were plenty of people disabled like me but they didn't get out a lot.

Sledd: At that point what did you learn about others with MCS?

Molloy: By 1982-1983 I'd learned there were other people whose lives had been changed abruptly in some of the ways in which mine had, and they were described as having "Environmental Illness." We called it "EI." I realized that we'd landed on the map when someone sent me a Sunday, October 30, 1983 L.A. Times article entitled "Victims of Rare Illness Allergic to Everything" by staff writer Lee Dye.

The article featured Phyllis Saifer, M.D. and patients in her Berkeley practice, and they were chemically sensitive. Clearly, I wasn't the only person with such an illness. Dozens of people in California alone had the same thing I did. A friend found a support group for me and I did get to go to two meetings, of the Environmental Illness Association, at the old ballroom at San Francisco's French Hospital. The support group included people living with variations of what had happened to me. They reported searching everywhere to find clothes that didn't make them sick, some way to wash them, the pain of bathing in tap water, difficulties finding food when they couldn't enter stores and the grocers refused to go outside.

These people had become helpless, frightened the same as I was. They too faced what amounted to daily assaults. They faced effective eviction, from wherever they'd found to stay, when their neighbor would spray for ants, someone would walk by smoking a cigarette, the landlord would dry clean the draperies. People were out on the street with what they could carry of their now contaminated possessions. Several people were sleeping in their vehicles. One was a businessman still struggling to work in the financial district. He couldn't change his clothes and he slept in his station wagon, out near the ocean. His career was crashing, and he'd never see insurance or Workers Comp because his illness was too mysterious to explain. There was a Palo Alto woman who'd become horribly sensitized, was living in the yard of her own house, and was losing her marriage. Her husband had simply had it. Even the people who were well to do couldn't buy their way out of this. There was no cure, no remedy, no help, and no recourse through the legal system. Clearly, what was happening to us was more than an illness.

It wasn't until later, when I was exposed to Humboldt Access Center, that I began to see civil rights as a concept that might help us defend ourselves, defend each other.

It was my nervous system that took the hit from environmental exposures. My gait was affected due to movement disorders (dystonia and clenching), triggered by specific, common chemical and electrical exposures. By a few years later, I needed a wheelchair to leave home. My speech was sometimes unintelligible. I pinned notes to my clothes in case I had to get help. Over time, it all resulted in my learning a little about mobility impairment, speech and learning disorders, lost focus and concentration, and resentment at being dependent.

Sledd: Right - so is that when you became more politically active?

Molloy: From that first ILC, Humboldt Access Project, that I visited through the window I got literature. The article I read over and over was “Guide to Section 504” by Peter Coppelman, from the Summer 1977 issue of “The Independent, A New Voice for People with Disabilities” published by Berkeley’s Center for Independent Living. (Yes, I still have a copy.) It said Section 504 of the U.S. Rehabilitation Act states that people with disabilities can have the expectation that public facilities and programs would be accessible. People with other disabilities had fought to achieve at least this expectation of access. But why did it seem as though we weren’t given even the chance to try? It felt like maybe we’d missed the last boat, and those on board weren’t looking back. Could we catch up, and be part of this effort?

What drove the Disability Rights movement was newfound self respect, fierce loyalty to people even less able to cope with the system, and a “no prisoners” attitude. EI people were way behind, still unsuccessful at bringing our access issues out into the open, but I could see no option, but for us to get to work and do it. I decided to volunteer for the board of Humboldt Access Project in Eureka. I envisioned an educational exchange where I’d learn the “nuts and bolts” of ILC management and the board and staff would learn about EI.

It was a near total failure. I got so sick at the board meetings that my contributions had no value. I’d sit outside on the porch, horribly ill, and one night I even blacked out. I got sicker and sicker trying to participate in the board meetings. I couldn’t hold my own with the other people. I couldn’t understand that my participation was useless to them and dangerous for me. Then the agency got a new director, Dr. Devva Kasnitz. She listened and she paid attention. I told her I thought there might be dozens of people in California alone with this kind of a disability, variations of Environmental Illness, and they were going completely unserved by the IL Centers or any

other social service agencies. Devva told me to do an intake on everyone I could locate, and find out whether they were able to get benefits and whether they could go to public places.

Devva was sophisticated about the politics and finances of disability agencies, and I did what she said. Within six weeks I’d done intakes on well over 100 people in California who were not just ill, aggravated, or inconvenienced by Environmental Illness, but who were truly disabled. When I contacted one person with this illness, they’d know a couple of friends who had it too. Many had no phones, so I’d go try to find them. I met a lot of people. As a result of the brutal stigma of the times, there was developing an underground network of people with this condition. To some degree, it remains that way.

Devva had helped me begin the process of turning this sickness into a disability. I learned to push on behalf of people who were in worse shape than I was. Humboldt Access Project’s facility was still deadly sickening. At one point, a new carpet was glued down and other people on the staff became sick too, even though they didn’t identify as Environmentally Ill. We wondered whether people with other disabilities might be impacted by chemical exposures, but in different ways. We started keeping notes on avoidable errors in construction, remodeling, and maintenance that were jeopardizing people in the two-dozen ILCs up and down the state of California.

My employment at the Humboldt Access Project lasted only 5 months, but it gave me a start at the education I wanted. With backing from one of the community outreach programs at Humboldt State University, I started a newsletter for people with environmental illness called “The Reactor.” I wanted it to be a primer on disability rights – a way we could “catch up” with people who had other disabilities and were accomplishing groundbreaking work. I liked the name

“Reactor.” Individuals who’d become so sensitized that they reacted to absolutely everything were referred to in those days as “universal reactors.” Besides I enjoyed the dynamic, explosive sound of it.

That year, I got married and moved back to the S. F. Bay Area. My personal stamina had improved to the point where on occasion, I could have productive, if careful, contact with people. I found myself a new ILC home at San Francisco’s Independent Living Resource Center. They helped organize outreach work to all the ILCs I could get to in California. I got sick if I stayed inside any of them for more than a couple minutes, but we all learned a lot.

I found in the course of interviewing people with EI around the state that they had no more idea what an ILC was than I’d had. However, they too were denied access to services, disability benefits, housing, and any protection under the law. It seemed like I needed a better technical background to work with the ILCs, and other social service agencies, and the EI people’s families. An Urban Studies professor, Dr. Debra LeVeen at San Francisco State U., helped me design a Masters program, through the Department of Public Administration, through which I could study Disability Policy. During the following years, I found my way to Washington, D. C. agencies and elsewhere for conferences and presentations, seeking allies with whom EI people could work.

In 1992, after five grueling years of graduate school, I moved to the high desert of Northeast Arizona. By that time, various support groups in the U.S. and abroad were publishing good newsletters, and the online discussion and advocacy groups had come into their own. It was no longer essential to work so hard on “The Reactor,” so I stepped down as editor in 1994. Once moved and adjusted, I represented the NE rural part of Arizona on the Statewide Independent Living Council for three and a half years. I still participate on the

Housing Subcommittee of National Council on Independent Living, and on the Indoor Environmental Quality workgroup convened by the U.S. Access Board to chart our course. Great, challenging experiences, all over my head, all wear me out.

I’ve worked part-time, usually from home, for New Horizons Independent Living Center based in Prescott Valley, from its inception in 1994. I’m often asked why I’m so unafraid of losing my monthly Social Security Disability pittance, since I always report on the books the work for New Horizons or any other agencies that give me a chance. It isn’t that I’m brazen or have a “make my day” stance toward the Social Security Administration. It’s that although I’ve worked as much and as hard as I’m capable of with the ILCs for years, they’ve never paid me (or any other employees for that matter) enough to jeopardize my \$253 per month. Honest, we don’t go into this field for the big bucks, no matter how it looks from the outside.

Sledd: So you just mentioned some of your successful attempts and failures in advocating – are there any more that you didn’t already mention that stick out in your mind?

Molloy: I’ve participated in 25 years of Independent Living Center efforts that mostly didn’t work, and a few that turned out OK. There’s just enough positive reinforcement to keep me trying. There are some very dead ends to pursue and sometimes it seems like I’ve gone after most of them. Then I find out no, there are more. The concept of “Disability Rights” presents a moving target. There is no manual.

Sledd: Do you have any specific projects that you’ve organized yourself that you can talk about?

Molloy: I work hardest advocating for affordable accessible housing for people who have chemical and electrical sensitivities – particularly those who are also mobility impaired, a huge percentage of our population.



There is substantial crossover among people with various orthopedic and brain injuries and those of us with chemical and electrical sensitivities.

Sledd: So you worked on that a lot?

Molloy: Accessible housing is where I spend the most effort and work the hardest, and have had the most failures. A couple of projects have gone all right. I'd never have believed how slowly the progress has come or I'd never have tried.

Sledd: If everything worked out the way that you wanted it to, what would be your major overall accomplishment?

Molloy: Had you asked 20 years ago, I'd have said I wanted us integrated into the greater independent living and disability rights movement. At this point I have to modify that goal. I don't see that we'll survive if we strive to integrate at the expense of our safety. It is too threatening to be integrated with people who disrespect our requirements. Our quality of life issues are huge. We can be incapacitated by common everyday exposures. A seemingly small risk for our non-EI colleagues presents a huge assault, with disparate impact to us. We have to maintain the option of being separate, then as equal as possible.

Sledd: So you would say that that is a major goal for you?

Molloy: We need separate areas that are safely accessible to us in public facilities and in housing.

Sledd: Well I definitely think that you're right, as you can't get everybody to comply - it is almost impossible.

Molloy: I see us needing one good accessible room and path of travel - entryway, hallway, restroom, water fountain, public phone - per hospital, social services agency, educational facility, all those entities that now make life

and death decisions about us regarding, for example, surgery or child custody, without the benefit of meeting us. For the people too sensitized to safely approach any facility whatsoever, or who can't ride in a car or a bus to get to a public facility, telephone or fragrance-free home appointments can be preferable to no appointment at all.

Essential for us would be hospitals, clinics, medical centers, a courtroom, and areas of refuge for use during emergencies. Anyone with the illness has had outdoor appointments with medical or social services staff during which a bus pulls up, vehicles idle, people walk by smoking or wearing fragrance, someone paints or applies cleaning and maintenance products - exposures that make us too sick for the appointment to have been worth the effort. Plus, in an outdoor appointment, our current option, there's no confidentiality. Anybody hears about our personal medical issues, whether we qualify for food stamps, how our kids are behaving in school, or whatever. It's degrading. Think about having your next annual exam in the hospital parking lot.

Sledd: You wouldn't think it would be that hard to make the most basic resources accessible, especially given the prevalence. I've noticed when we've been researching that it's way more common than one might think.

Molloy: Might it not be construed as fraud, possibly criminal negligence, on the part of tax-supported entities to deny services to people on the basis of our having a certain disability, certain access requirements? To this day, even the ILCs themselves hold us to a higher standard than people with other disabilities. We have to be medical experts with attractive personalities to explain our functional impairment to ILC gatekeepers. This is not OK. We need the civil right to access, not individual favors.



Sledd: What has been the most rewarding part overall for you in your many years of advocating for MCS/ES??

Molloy: Advocates with other disabilities are now somewhat less likely to leave us out on the sidewalk and forget about us. That used to be the norm. That's what happened during the work on regulations to implement the A.D.A., and we still live with the repercussions. Those days are not over, but there are fewer of them.

Sledd: So you think being involved in everything, right in the middle of it, has made you appreciate the small progress more so than if you were not involved?

Molloy: We've been turned away at critical junctures, and it is likely to happen again. Some of the people in leadership positions have found it too hard to stand by us, fearing that we are too much a political liability. However, knowing some of the history helps me keep working on our projects without wanting to fall on my sword.

Sledd: So how do you now view the tactics that you have taken?

Molloy: We'd be in much better shape had we not stalled around waiting for approval and acceptance from other groups within the disability rights movement. I have to take responsibility for aspects of this error. My faith in the value of cross-disability work, and my hope that we'd become integrated, were substantially overblown. I am more useful and down to earth now. I chase fewer illusions but my aim is better.

Sledd: So what are you looking forward to doing in the future?

Molloy: We've just finished four safer-than-average wheelchair accessible rental houses in our neighborhood, for people with moderate chemical and electrical sensitivities. What an honor, to have gotten a chance to help get those up and running. Dream come true?

There will be housing, plenty of housing for people with any and all disabilities, built and maintained using safe materials, all over the country.

Also, we might be able to create an ILC here in the mountains during the next couple years. We would start it as a satellite of an existing center, then later, stand on our own.

Sledd: That's a respectable goal. And, from what I have learned, I definitely agree that housing is a crucial issue.

Molloy: It's primary. As of now, we don't have a right to stay in even marginally accessible apartments, because convention and the law support neighbors who smoke, light incense, use dryer sheets, spray their rose bushes, idle their motors, or otherwise effectively drive us out.

We'll keep working toward accessible affordable safe housing for people with sensitivities. I wish housing were less toxic for everyone, disabled or not, but I don't waste time arguing about it any more. I'm busy.

Sledd: People shouldn't be living in cars or be homeless just because they're disabled.

Molloy: No one should have to live isolated in a car while exhausted, in excruciating pain, threatened by every whiff of smoke, every power line, every stranger.

Sledd: And you live in a home right now?

Molloy: I live in a small, sturdy, safe (for me) house in a neighborhood where most of the people have chemical and electrical sensitivities. Each of us had become dysfunctional in the various urban environments where we'd built our lives so we risked all and moved out to the high desert in Northeast Arizona. Some of us can visit each other, help with chores, and go outdoors almost whenever we want to without oxygen tanks. It's segregated, it's isolated - everything the rest of the independent living

movement is fighting to get away from. But what other model exists that can work, at least during this generation, while the larger culture hasn't yet begun to get used to us?

Research Team Note: Services and accommodations for persons with disabling environmental sensitivities remain uneven and problematic in most service venues.

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**Poetry by Robert M. Hensel***Nature's Dance*

I sit ashore this moonlit beach.  
 Where water, and sand, come to meet.  
 As waves crash against the sandy ground,  
 together they will dance to nature's sound.  
 One step, two steps, onto the shore.  
 Then comes back to dance some more.  
 This rhythmic view, I've come to glance.  
 The life that's found in nature's dance.

*Nights Reflect*

Shadow puppets on the wall.  
 Dark carbon copies of what a  
 furnished room bares.  
 Into a black covered mirror,  
 my world reflects.  
 Showing me things,  
 only the night has to offer.

*Peaceful Ground*

Cool morning spit on bladed grass.  
 A thousand silky fingers tickling toes.  
 The strong scent of nature's freshly cut hair.  
 Man's spiritual stomping ground  
 toward inner peace.

**Robert M. Hensel** resides in New York city. He was born with Spina Bifida and serves as an advocate for the disabled in an ongoing effort to better the rights of all Americans with disabilities. Robert is also a Guinness & Ripley's world record holder for the longest non-stop wheelie in a wheelchair, covering a total distance of 6.178 miles. <http://wheelierecord.tripod.com/>

## Book Review

**Title:** *Reading & Writing Disability Differently: The Textured Life of Embodiment*

**Author:** Tanya Titchkosky

**Publisher:** University of Toronto, 2007

**Paper ISBN:** 9780802095060, 192 pages

**Cost:** \$24.95 USD

**Reviewer:** Elizabeth DePoy

Titchkosky has written an important book that examines and showcases “disability meaning making.” Although she focuses her analysis on text, Titchkosky introduces the concept of enunciation early in her book, suggesting that what one learns from her analysis of delimited textual sources may be relevant to a broader domain of representations, utterances, and images that are part and parcel of our social universes.

In her introduction, Titchkosky reveals that as a means to posit views of disability that depart from the tragic deficit gaze; she aims to destabilize these narratives. What can be gleaned from a meticulous textual analysis are the lexical intersections, paradoxical representations, texts, and images that depict diverse meanings of embodiment, difference, and thus disability.

Before meandering through and deciphering meaning of printed texts, Titchkosky first takes the reader by the proverbial hand in Chapter 1 and introduces her major concepts. Although she claims that definitions are one form of text and further asserts she is not adding yet one more definition of disability to our lexicon, Titchkosky offers up what sounds like, looks like, and thus is taken by this reader as a definition of disability. However, different than the less esoteric model approaches to defining disability, Titchkosky locates it in process. That is, she asserts that disability is a “process of meaning-making” (p. 12). She then claims that understanding disability as process helps to illuminate the value scaffolding of embodiment in general, as it implies meaning, value, and devaluation of

diverse bodies. Her discussion of bodies, while not new to post-modern literature, nonetheless sets the boundaries for her subsequent analyses of axiology buried in texts. She delimits these sources primarily to those that approach bodies as subject and object, that speak of humans as “having bodies and being bodies” (p. 13) and that locate bodies in a socially choreographed movement of enactment or interaction. According to Titchkosky, regardless of narratives to the contrary, the only essential element that can be shared among the inhabitants of the disability club is that they are rendered, defined, and imbued with identity and meaning by text. To add dimension and complexity to her analysis, Titchkosky reminds us that texturing does not merely articulate a meaning in a document or image, but rather creates a tapestry of difference woven from the daily lives of individuals who interact with social, print and image sources of text.

Equipped with the central concepts that organize her analysis, Titchkosky then bifurcates the remainder of the book. Part One, containing three chapters, focuses on analyses of meaning of disability in diverse text sources. Part Two moves from definition to analysis of response to disability.

As the basis for her claim that disability is inscribed as a problem and thus devalued in comparison to “not-disability”, Titchkosky provides a cogent analysis of varied Canadian government texts (disability definitions, epidemiological data, census data and so forth). This thorough section provides the reader with the logic sequence that brings Titchkosky’s to her own understanding of community with text functioning as the integrative agent. Of particular interest to me was her discussion of survey items. In typical methodological lexicon, survey items are purported to emerge from conceptual definitions extracted from theory. Yet, Titchkosky turns this sequence on its ear, clearly illustrating how survey content creates and reifies constructs. Throughout this compelling chapter,

Titchkosky masterfully inserts criticism of the institutionalization of text meanings, and then indirectly points to alternatives without professing “what should be”.

Chapters 3 and 4 concentrate analytic energy on a single piece of text, revealing the nuanced way that horribilized medical meaning is constructed from the womb throughout life. In Chapter 3, Titchkosky further foregrounds the economic narrative that diminishes the value of disability constructed as medicalized alterity. In Chapter 4 Titchkosky posits “disability-as-negation” logic and its consequences for diverse individuals, larger groups, and for ideology (e.g. human welfare).

Parallel to Part One, Part Two begins with an analysis of Canadian government texts that guide responses to disability. Titchkosky’s introduction to this section reveals a sophisticated examination that moves beyond bemoaning disability as exclusion of people with medicalized embodied conditions. Rather, she suggests that the text of bureaucracy, inclusion and overcoming are important to investigate in order to rewrite, rethink and redo meaning. This assertion is then elucidated in the two subsequent chapters in this section. Of particular note is her discussion of the temporal sequence of alterity in which she demonstrates the operationalization of the points that she made about nomothetic survey methodology in previous chapters. Titchkosky skillfully analyzes text to reveal how segregation proceeds by reifying disability through survey and census counting.

Building on the previous chapter, Chapter 5 analyzes how embodiment is apprehended and sculpted by government texts. Moreover, in this analysis, Titchkosky illuminates how text on disability definition and management also creates and institutionalizes the meaning of non-disabled bodies and their control.

In Chapter 6, through unpacking texts that propose solutions to the disability “problem,” Titchkosky discusses the overcoming narrative,

its value contexts, and its “rise above” implications. As she notes, the overcoming narrative implies the condition to be overcome is heinous and invokes the advanced capitalist ideal of the rugged individual who achieves despite all odds. In these texts, body and self are separate creating the space in which atypical bodies can be ignored in favor of socially desired accomplishments.

Titchkosky does not neatly conclude her work with a summary and recommendations for change, as she asserts that the activity of unpacking and interrogating textualized disability in itself moves towards reframing meaning.

I learned much from my reading of this text and suspect that anyone else who would take the time to navigate the text would be simulated as well. Of course, I did find some claims that defied logic and might be revisited by Titchkosky in subsequent writings. For example, she claims that literacy is normative. First, literacy itself has multiple meanings particularly in a global, linguistically complex context in which electronic text is ubiquitous and unstable in its form.

Second, while she acknowledges that her own book is a text, she exempts herself from the “God Trick,” or the assertion of ultimate authority she ascribes to others. In doing so, she overlooks her own claims as grand narrative and would be better off challenging the reader and herself to turn her analytic strategies on the textured meaning she has created. Further, by not inviting interpretation of her own work, Titchkosky generates a hierarchy, perhaps unintentionally, of desired ways of knowing through her own preferences of hermeneutics and phenomenology. Moreover, she gives short shrift to the breadth of content in disability studies, as the field is fragmented with multiple perspectives that could provide more potent fodder for analysis.

Finally, implicit and sometimes explicit throughout the book is the equivalence between disability and impairment which I attributed to



the absence of language for alternatives. Titchkosky may have decreased this conceptual morass by finding language that would serve her aim of destabilizing this notion. Asserting her embodied diagnosis of dyslexia seems to be a poor fit in a book that proposed reading and writing differently.

The criticisms here are offered as challenges for Titchkosky's next works. Her book has made a significant contribution to the literature not only on disability, but on the broader discourse of diversity, difference, and change.

**Elizabeth DePoy, PhD** is professor of Interdisciplinary Disability Studies and Social Work at the University of Maine. Her most recent research aims to heal human-environment disjuncture through robotic access solutions. She may be contacted at [Liz\\_Depoy@umit.maine.edu](mailto:Liz_Depoy@umit.maine.edu)

## Book Review

**Title:** *Dissonant Disabilities: Women with Chronic Illnesses Explore Their Lives*

**Editors:** Diane Driedger & Michelle Owen

**Publisher:** Toronto: Women's Press, 2008

**Paper ISBN:** 978-0-88961-464-2, 258 pages

**Cost:** \$36.95 USD <http://www.womenspress.ca>

\$28.08 USD <http://www.amazon.com>

**Reviewer:** Carrie Griffin Basas, J.D.

Diane Driedger and Michelle Owen's edited volume, *Dissonant Disabilities: Women with Chronic Illnesses Explore Their Lives*, is a much-needed contribution to disability scholarship. It fills a space that still has room for other volumes yet to be written—research, literature, and essays on the experiences of women with disabilities.

Driedger and Owen solicited short pieces from women with disabilities around the world and this volume reflects that eclecticism. While

the book's editors are Canadian, the book also has contributions from Singapore, Australia, Scotland, and other countries. The works included range from social sciences to memoirs, and explore "invisible" to more visible disabilities and social and personal reactions to them. Many of the essays are moving and personal, such as Susan Wendell's "Notes from Bed: Learning from Chronic Illness." Wendell writes, "Can we value suffering without abandoning the effort to prevent or relieve it?" (p. 217). She and the other authors in the volume challenge the reader to consider how women with chronic illnesses are received by society and by feminism.

The variety and diversity of the work can be distracting, even distractingly dissonant, at times. The editors arranged the volume in five parts: "Clashing Expectations," "Unpredictable Bodies," "Disturbing Work," "Shifting Relationships," and "Traversing Dissonance." The reader is sometimes jarred by the lack of a transition from one piece within these parts to the next. The editors included an introduction to each part within the whole, but more of a bridge between the pieces would have helped the reader to see the connections between the pieces and the editors' reasons for selecting them.

Driedger and Owen remind us they performed light editing, if any, of the submissions and tried to let the pieces speak for themselves. Once the reader adjusts to the varied cadences, the effect can be positive as well. Women with chronic illnesses explore their lives and illnesses (e.g., depression, cancer, anorexia, chronic fatigue, chemical sensitivities, fibromyalgia, bipolar disorder, chronic pain) with candor and detail, as do their partners, friends, and allies.

The reviewer can see this volume being used within college and university classrooms as a jumping-off point for a discussion on the varied experiences of women with disabilities. This book could also be a satisfying read for anyone with a disability who has felt underrepresented in existing collections of essays and memoirs.

The voices are those of a group of diverse, dynamic women claiming their experiences and staking valuable discursive territory.

The editors and the authors undertook a grand project in putting together this volume. In doing so, they encourage others to take on similar projects in greater depth or detail. This book is a commendable start to a series of works in this area.

**Carrie Griffin Basas** is a Visiting Assistant Professor at the University of North Carolina, Carolina School of Law in Chapel Hill, NC. She may be contacted at [cbasas@gmail.com](mailto:cbasas@gmail.com)

## Book Review

**Title:** *An Oral History of the Education of Visually Impaired People: Telling Stories for Inclusive Futures*

**Editor:** Sally French

**Publisher:** Lewiston, NY: Edwin Mellen Press, 2006

**Cloth ISBN-13:** 978-0773457065, 484 pages

**Cost:** \$129.95 USD

**Reviewer:** Beth Omansky

As a long time fan of Sally French's work, I confess I approached *An Oral History of the Education of Visually Impaired People* from a positively biased standpoint. This, however, could have worked against the book because my expectations were high and I might well have been disappointed. I was not.

This book offers a disability studies perspective on the history of blindness education in Great Britain as lived by 61 research participants from England, Scotland, Northern Ireland, Wales, and the Channel Islands. The lived experience of people with visual impairments in residential schools reveals themes of abuse and friendship, social isolation and isolation from

family, personal identity development, and how social prejudice affected standards of education from post-World War I to the current era.

The book is divided into six sections. The introduction "Telling Stories"; part one "The Early Development of Education for Blind Children"; part two "Stories from the Segregated Past, 1920 to 1944"; part three "Stories from the Special Education System, 1944 to 1981"; part four "Stories from the Special Educational Needs System, 1981 to 21st Century"; and the conclusion "Lessons for Inclusive Futures."

French provides an in-depth historical backdrop at the beginning of each section that helps the reader understand how public policy and world events would be revealed in the participants' stories.

This book marks the first time the oral history of blind children has been collected. Because French participated in special education she positioned herself as an 'insider' researcher, and included her own personal experience. Reports of institutionalized abuses, broken family relationships, loneliness, social and personal isolation, and powerlessness are sometimes emotionally difficult to read about, such as the story of school officials taking the pocket off a little girl's pinafore where she had been hiding the distasteful meat they served. Some students reported that the teachers sometimes hit, pinched, or pushed, and for any minor offence, a child might have to "sit in silence and you'd have to go without jam on your bread all week and cake on Sunday and you had to clean the little ones' shoes" (p. 56). As dismal as some of the students' experiences were, others were tales of academic and career success, deep lifelong friendships, and personal resilience – of "survival, collective empowerment, affiliation and resistance" (p. 413). The stories cover kindergarten through university by people who went into a variety of professions ranging from sheltered workshops to law, social work, nursing, and physiotherapy.

Because the stories are related in the participants' vernacular, their personalities shine through spiritedly and keep readers engaged. As in previous works, French's use of the personal as political makes the book quite suitable for historians, blindness educators, oral history researchers, rehabilitation workers, and anyone interested in how to apply the social model of disability to education and public policy. This work is another example of French's commitment to providing spaces for disabled people to tell their stories from their perspective rather than historically typical reporting of the disability experience by nondisabled professionals. French examines both diversity and commonalities within the stories, and concludes the participants' accounts make clear that "inclusion means far more than accessing the curriculum or moving around buildings. Inclusion induces a powerful psychological dimension of belong-

ing" (p. 412). French asserts, "It is possible to experience inclusion in a segregated school and exclusion, or isolation, in a mainstream school (p. 411), and therefore, 'inclusion' must be a thoughtful, meaningful process.

As is often the case with research books with a limited audience, the hefty price could be a bit prohibitive for the average student, but it certainly is a worthwhile addition to public and university libraries, not just in Great Britain but around the globe. This book is a brilliant addition to disability studies and blindness education history.

**Beth Omansky, Ph.D.** is a disability studies scholar and community activist in Portland, Oregon, USA.

## Disability Studies Dissertation Abstracts

\*\*\* Editor's Note: This is a new section of RDS courtesy of Jonathan Erlen of the University of Pittsburgh. Abstracts listed below are selected from a full list of disability-related dissertation abstracts updated quarterly. The full list is available at: [http://www.hsls.pitt.edu/guides/histmed/researchresources/dissertations/index\\_.html](http://www.hsls.pitt.edu/guides/histmed/researchresources/dissertations/index_.html).

*Students who are Deaf/Hard of Hearing with interpreters in the foreign language classroom*  
Kilpatrick, James E., Jr.. Proquest Dissertations And Theses 2008. Section 0099, Part 0282 147 pages; [Ph.D. dissertation]. United States -- Kansas: University of Kansas; 2008. Publication Number: AAT 3337113.

*Friendships of preschool children with disabilities: The role of child, adult, and program characteristics*  
West, Tracey. Proquest Dissertations And Theses 2008. Section 0153, Part 0451 150 pages; [Ph.D. dissertation]. United States -- North Carolina: The University of North Carolina at Chapel Hill; 2008. Publication Number: AAT 3331056.

*Peer reciprocity, acceptance and friendship quality in children with autism in general educational settings*  
Lee, Lisa Sea-Yun. Proquest Dissertations And Theses 2008. Section 0031, Part 0525 55 pages; [Ph.D. dissertation]. United States -- California: University of California, Los Angeles; 2008. Publication Number: AAT 3335941.

*Graduate students' perceptions of online learning in a multiple disabilities education course*  
Ewing, Karen Marie. Proquest Dissertations And Theses 2006. Section 0505, Part 0745 158 pages; [Ph.D. dissertation]. United States -- District of Columbia: Gallaudet University; 2006. Publication Number: AAT 3337509.

*An analysis of student satisfaction rates in deaf first year college students*  
Kennedy, John Parker. Proquest Dissertations And Theses 2008. Section 1351, Part 0727 114 pages; [Ph.D. dissertation]. United States -- Minnesota: Capella University; 2008. Publication Number: AAT 3337358.

*A qualitative investigation of the educational experiences of two students with significant disabilities across their school careers*  
Bock, Steve A.. Proquest Dissertations And Theses 2008. Section 0099, Part 0529 190 pages; [Ph.D. dissertation]. United States -- Kansas: University of Kansas; 2008. Publication Number: AAT 3337076.

*Inclusive educational practices for students with disabilities within the European Union*  
March, Evangelia. Proquest Dissertations And Theses 2008. Section 0090, Part 0529 292 pages; [Ph.D. dissertation]. United States -- Illinois: University of Illinois at Urbana-Champaign; 2008. Publication Number: AAT 3337860.

*Parents involvement in transition planning for their young adult children with intellectual disabilities*

Martinez, Donna Claire. Proquest Dissertations And Theses 2008. Section 0075, Part 0516 420 pages; [Ed.D. dissertation]. United States -- District of Columbia: The George Washington University; 2008. Publication Number: AAT 3331458.

*Minority and non-minority students with disabilities in higher education: Are current university policies meeting their needs?*

Walker, Duronne K. Proquest Dissertations And Theses 2008. Section 0090, Part 0529 117 pages; [Ph.D. dissertation]. United States -- Illinois: University of Illinois at Urbana-Champaign; 2008. Publication Number: AAT 3337955.

*Deaf teachers in China: Their perceptions regarding their roles and the barriers they face*  
Yang, Jun Hui. Proquest Dissertations And Theses 2006. Section 0505, Part 0529 194 pages; [Ph.D. dissertation]. United States -- District of Columbia: Gallaudet University; 2006. Publication Number: AAT 3337510.

*The influence of gender and disability on leadership and management potential*

Chavez, Cescilio Briseno. Proquest Dissertations And Theses 2008. Section 1210, Part 0454 105 pages; [Ph.D. dissertation]. United States -- Texas: Our Lady of the Lake University; 2008. Publication Number: AAT 3339608.

*Deaf women's satisfaction with prenatal care*

O'Hearn, Amanda Michelle. Proquest Dissertations And Theses 2000. Section 0505, Part 0451 122 pages; [Ph.D. dissertation]. United States -- District of Columbia: Gallaudet University; 2000. Publication Number: AAT 3337517.



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