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## Mad at School

Price, Margaret

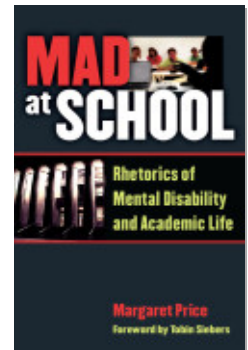
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## In/ter/dependent Scholarship

WITH LEAH (PHINNIA) MEREDITH,  
CAL MONTGOMERY, AND TYNAN POWER

I didn't pay much attention to independent scholarship until I arrived on its doorstep, so to speak, by way of mental disability. I can date my attentiveness to an email exchange with Cal Montgomery in 2007. In April of that year, I wrote to Cal—having read her work in *Ragged Edge Online*—to ask if we might meet at the upcoming SDS conference. Cal responded warmly to exchanging ideas by email, but said she would not be at the conference, since she had attended some years before and found it an “access nightmare.” Although I probably should have realized earlier that SDS, even with its efforts to provide access for all members, remains an inaccessible space for many, Cal's note was nevertheless a revelation. Her chance remark led me to further research into the accessibility of conference spaces (Price, “Access Imagined”), and has helped me develop my theory of kairotic space—particularly the disturbing question of whether the kairotic spaces of academe are *by their very nature* poorly accessible to those with mental disabilities. It also led me to conduct further research into independent scholarship.

Institutions of higher education in the United States now employ *more* independent scholars than their counterparts—should we say “dependent scholars”? However, the foregoing claim depends upon how one defines *independent scholar*, and definitions vary widely. Some suggest that all persons employed as instructors in higher education who do not occupy tenure-track or tenured jobs should qualify. For example, Barbara Currier Bell, writing in a 2004 edition of the newsletter from the Center for Independent Study, argues that only one-quarter of new faculty hires hold “regular,” that is, tenure-track jobs, and notes that the

majority of “term” hires are women. Bell suggests that “the ‘full-service’ white male professor is already the faculty equivalent of the spotted owl” (“Independents” 1). Scholarship in composition and rhetoric often uses the term *contingent faculty*, noting that such faculty are “often neither part-time nor adjunct in the true sense of those words” (Schell and Stock 15). Further investigation reveals a huge array of definitions and related terms, including *contract scholar*, *scholar-for-hire*, *hobby scholar*, *gypsy scholar*, *scholar-at-large*, *liberated scholar*, *private scholar*, *freelance scholar*, and most piquant, *intellectual* (Bell, “An Independent Scholar” and “Independent Scholarship”; Schell; Wentz).

An important distinction to note is between those whose primary means of support is teaching and those whose primary means of support comes from elsewhere. Discussions that use *contingent faculty* tend to focus on those whose livelihood comes from teaching—for instance, term hires or, in some cases, graduate students working as TAs. However, discussions that use *independent scholar* tend to define these workers differently. In a 2004 survey of the National Coalition of Independent Scholars, David Sonenschein found that only 7 percent of respondents who were working identified their primary work as teaching (17). I make this distinction not to pull the two groups apart, since they do overlap considerably and have many common concerns, but to clarify my own purposes for this chapter. While many academics with disabilities do work as contingent laborers because of institutional barriers that prevent them from accessing conventional tenure-track jobs, my interest for the present study is disabled academics for whom even the path to part-time teaching work is barred. For example, some scholars with mental disabilities may not be permitted to enroll in postsecondary institutions in the first place; and at least one postsecondary degree, if not two, is the usual prerequisite for university teaching work. My point here is that, although the situation of contingent faculty is important, such faculty members have already found ways past a primary access barrier—the “moat” that guards postsecondary education in general.

Fueling my interest in independent scholarship is a rhetoric of “choice” that seems to enter discussions of academics who do not teach, or teach only rarely. In their often-cited 1993 study *The Invisible Faculty*, Judith Gappa and David Leslie propose and elaborate four categories: “career enders”; “specialists, experts, and professionals”; “aspiring academics”; and “freelancers” (49–63). While Gappa and Leslie pay careful attention to limiting factors, including “lack of geographical mobility”

(56) and “gender bias” (57), it is notable that their profiles of contingent faculty include frequent mention of choice. For example, one person who “exemplifies the freelancers” “*prefers* not to have any greater involvement in the institution because she values the free time she can devote to her other roles and activities” (61; emphasis added). I am worried less by the data included in the study by Gappa and Leslie, a valuable work, than by who is left out: how many contingent faculty or “aspiring academics” do *not* have so much choice in their access to academic discourse? What are the stories of their decisions—and are we comfortable calling their decisions “choices,” given how circumscribed access to academe can be? How well have these persons been represented in studies so far? How often is disability a factor in the hard “choices” that must be made?

Research on contingent faculty, while still receiving less attention than it should, nevertheless has proliferated and gained increasing authority over the last several decades. “Working Contingent Faculty in(to) Higher Education,” by Eileen Schell and Patricia Lambert Stock, provides an excellent overview. Schell and Stock document the movement of research about and by contingent faculty from its origins in the social sciences, which tended to provide aggregated data and composite profiles, through further waves of research that include personal testimonials, “ideational” calls for large-scale reform (29), and reports of specific changes occurring in local contexts.

But it’s important to notice that much of the research on contingent faculty is located *within* academe. For example, the article by Schell and Stock is the editors’ introduction to a collection published by NCTE, an academic press, and I would be able to find most of the sources it cites by visiting databases such as JSTOR and MLA, consulting academic periodicals such as the *Chronicle of Higher Education*, and drawing upon the book collection of a university library. By contrast, much of the research about independent scholars exists in a kind of gray space at the margins of academic presses and databases. A great deal of the research I gathered for this chapter, including reports and newsletters published by the National Coalition of Independent Scholars (NCIS) and the Center for Independent Study (CIS), was sent to me personally by independent scholars working for various organizations.<sup>1</sup> As I continued to investigate the situations of scholars who do not teach for a living—whether by choice or because of institutional barriers—I realized that a kind of information firewall exists between independent scholars and the conventional locations of academe, serving to reinforce inequities of status, recognition,

and material benefits. A poignant example of the power of this firewall comes from one of my personal communications with an independent scholar that preceded the writing of this chapter. Having learned my name through a listserv, this scholar emailed to ask if I would be willing to receive a copy of his life's work in the event of his death—an oeuvre that included, at the time of the email, six self-published books. This scholar knows that his work will not be immortalized in academically or commercially maintained archives, and therefore is exploring other means to ensure that his writing will survive beyond him.

How, then, shall I define “independent scholar” for the present study, given my attentiveness to the concerns of contingent faculty, but also my belief that there is a pool of academics “out there”—thinkers, writers, knowers—who are barred from access to conventional academic arenas such as classrooms and conferences? I begin with the definition offered by Ronald Gross and Beatrice Gross in their 1983 study *Independent Scholarship: Promise, Problems and Prospects*. Gross and Gross suggest that, while the range of people who might be called “independent scholars” is diverse, “they share two defining characteristics: they are pursuing serious, intellectual inquiries outside academe [characteristic 1], resulting in findings that have been accepted by fellow scholars as significant contributions [characteristic 2]” (2). I want to unpack each of these defining characteristics more carefully.

First, let's consider the status of “serious, intellectual inquiries.” Who decides what is serious, and what is intellectual? We could say that independent scholars should publish peer-reviewed articles in scholarly journals, which are then indexed in heavily subscribed databases such as JSTOR, MLA, or PsychArticles. Yet many independent scholars operate outside, or at least at the margins, of these privileged domains. For example, Cal Montgomery, one of the independent scholars interviewed for this chapter, has published extensively in the online magazine *Ragged Edge Online*. Montgomery's contributions have been cited repeatedly in scholarly articles—that is, articles that appear in peer-reviewed journals indexed in databases such as JSTOR. Yet her articles *themselves* do not usually appear in these scholarly databases. Second, let us consider the status of “fellow scholars.” While Tynan (Ty) Power, another independent scholar I interviewed, has attended, presented at, and in some cases organized conferences for groups including Al-Fatiha (an organization for LGBTQ Muslims), and has published in “alternative” locations such as the anthology *Pinned Down by Pronouns* (Conviction Books, 2003), it

is questionable whether this sort of activity would meet the standard set by Gross and Gross of “serious, intellectual inquiry,” nor whether Power’s readers and listeners would be considered “fellow scholars.” Much of Power’s writing appears on the blog site LiveJournal, and is often password-protected. Some of the LiveJournal posts are quite clearly scholarly—for instance, an extensive post about Ramadan, combining Power’s research on Islam and data from his personal experience, which is updated and reposted each year. Many members of Power’s audiences are graduate students, professors, instructors, or researchers. And yet, since we exist on LiveJournal only as unaffiliated entities such as “mirmormargaret,” it is debatable whether the interlocking threads of our comments would be deemed “scholarly” conversation, and by whom. To be fair, the report by Gross and Gross was published decades ago, well before the question of Internet authorship arose. Yet the questions remain: Who decides what is *serious* and *intellectual*, and which persons qualify as *fellow scholars*?

For the purposes of the present study, I want to extend the boundaries of the definition, and to change the terms a bit. I begin with this claim: Academic inquiry investigates questions salient to our material and discursive lives; conducts this investigation with a level of rigor appropriate to the context; and is attendant to responses from others concerned with similar questions. Anyone engaged in such inquiry, I believe, can lay claim to the name *independent scholar*, if wished. This is the working definition that led me to the selection of participants in this small qualitative study. These are people whom I know in contexts outside the study, and whom I know largely online—as friends on LiveJournal and Facebook, as email correspondents, as passionate writers and thinkers whom I never run into at conferences. That, to me, is part of the point: I *don’t* meet them at conferences. An important aspect of this study’s methodology is its aim to record experiences from persons whose views are not readily accessible through conventional academic channels.<sup>2</sup>

### The Role of Disability in Independent Scholarship

Just as research by and about independent scholars is hard to find in conventional academic spaces, recognition of the significant role that disability might play in an independent scholar’s life appears to be similarly unnoticed in research by and about independent scholars. In Sonenschein’s 2004 study *Independent Together*, for example, a survey of 286

NCIS members collected extensive demographic information on topics including gender, age, race, ethnicity, region, marital status, degrees obtained, financial situation, and languages spoken or read. Yet in this sixty-three-page report the word *disability* does not appear once. To be sure, related data were collected—including information on members' health insurance, employment, and (in a few cases) roles as “caregivers” (50). While reading, I wondered: Isn't it possible that a significant proportion of independent scholars have disabilities? Why aren't their experiences better recognized?

I based this supposition on research by DS scholars who have documented the inaccessibility of academe's conventional system of tenure, promotion, and reward for persons with disabilities. A chilling example comes from Paul K. Longmore's “Why I Burned My Book.” In this essay, Longmore describes his path toward academic employment, including encounters with undergraduate and graduate professors who told him things such as “no college would ever hire me as a teacher” (232), and eventual achievement of a Ph.D. in American history in 1984. Using his own experience as a case study, Longmore demonstrates the means by which public society at large, including academe, has made itself inaccessible to scholars with disabilities. For example, Longmore was blocked from gaining teaching experience as a graduate student, since even part-time work as a TA or instructor would have forced him to risk giving up government benefits that paid for his in-home assistants and his ventilator—“the aid that enabled me to live independently and, in fact, to work” (237). In other words, experience crucial to his professional development was disallowed on the grounds that engaging in such work would undermine his status as one who “needed” accommodations such as in-home assistants. According to government definitions, if one is disabled enough to receive benefits, one cannot work; and if one can work, then one must not be disabled enough to qualify for benefits. Longmore's essay vividly portrays this catch-22:

Necessity has forced many of us [among the severely disabled] to maintain eligibility for federal Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) or both . . . [which also] make us eligible for other, more essential assistance. For instance, throughout my adult life I have paid my personal assistants through California's In-Home Support Services program. Medi-Cal (the California version of Medicaid) has paid for my ventila-

tors. Without this financial aid, I would have had to spend my adult life in some sort of nursing home. . . . Independent living has allowed me to work productively.

The catch is that for most of my adult life, in order to maintain eligibility for this government aid, I have had to refrain from work. Using a combination of medical and economic criteria, *federal disability policy defined—and still defines—“disability” as the total inability to engage in “substantial gainful activity.”* (236–37; emphasis added)

This is a rhetorical and material paradox similar to that noted in the ADA case-law discussion from chapter 3. In order to qualify as “disabled,” faculty members must display a certain (implicitly measurable) “level” of impairment; yet if they display that level of impairment (“severe” or “total” or whatever), they are presumed unfit to work at their chosen profession.<sup>3</sup> Longmore’s story is a saga of political action, letter-writing, and wrangling with bureaucratic definitions in his efforts to engage in work as an employed scholar while still obtaining the accommodations that would enable him to exist outside of a nursing home. Despite all his efforts, he learned that he would not be allowed to earn royalties from his first scholarly book (*The Invention of George Washington*), which had taken him ten years to write, without losing his SSI/SSDI benefits. In response, he burned a copy of the book in a public protest on October 18, 1988.<sup>4</sup>

Although wheelchair users, like Longmore, are the group most likely to be classified as “unemployed” because of a disability, those with mental disabilities constitute a large group as well. In its 2007 annual report, the Social Security Administration (SSA) reported that 2.2 million Americans receive Social Security benefits because of “mental disorders” (excluding “retardation”). This number represents more than 27 percent of all disabled beneficiaries. The large percentage of SSA beneficiaries with mental disabilities has attracted attention from scholars, mostly within public health, psychology, and psychiatry. For example, in 2008 Ronald C. Kessler and coauthors published a paper claiming that serious mental illness (SMI) caused an estimated \$193.2 billion loss of personal earnings in the United States during the year 2002.<sup>5</sup> Tellingly, the press release from the National Institute of Mental Health (NIMH) announcing Kessler’s findings is headlined “Mental Disorders Cost Society Billions in Unearned



Income.” The original study does not say that mental disorders “cost society” anything, although it does use terms such as “societal burden” (708), which is a discipline-specific term in public health. Note, then, the way that the significance of the findings is twisted when it travels from original study to press release. The publicly available online NIMH press release, which is likely to have many more readers than the original study from the *American Journal of Psychiatry*, could have interpreted the findings from Kessler and coauthors in another way: namely, that *society* (in the form of access barriers) costs *people with mental illnesses* billions in annual income. Yet it twice uses the phrase “costs society,” thus implying that the societal burden is the fault of persons with SMI.

At any rate, the problem remains clear: millions of people with mental disabilities receive benefits that depend upon the judgment that they are unable to work, or can work only in very limited capacities. If we put this number together with Longmore’s point that receiving necessary benefits often bans the recipient from engaging in “gainful” employment, we can conclude that persons with disabilities who wish both to receive treatment or accommodations *and* to earn money for their work are caught in an insidious bureaucratic and rhetorical paradox. I noted in chapter 3 that academics with disabilities may “need” full-time employment in ways that nondisabled academics do not, in order to obtain health insurance. But it is also true that in some cases, academics with disabilities may “need” *not* to have full-time employment, lest they lose government-sponsored benefits. I call this *the un/able paradox*: If one is deemed “unable” to work, then one qualifies for the accommodations that would make work possible; yet if one makes use of those accommodations and does work, then one is deemed too “able” to qualify for accommodations, whose loss makes work (and in some cases, life) impossible.

Questions of health care, employability, and the intersection of one’s everyday life with the terms of one’s employment are shared by most academics (and most workers, for that matter). However, these questions take on highly complex and specific shapes when we consider the situation of academics with mental disabilities. Researching the experiences of academics with mental disabilities who operate outside the conventional structures of academe does more than bring forward the experiences of an underrecognized group; it also calls into question the very notion of “independence” in scholarship, including the process of scholarly research itself.

## Disability Studies Methodology: Putting It to the Test

Sonenschein suggests in the introduction to *Independent Together* that in-depth, open-ended interviews would be “the next logical step” of investigation into the lived experiences of independent scholars (5). In the rest of this chapter, I report on interviews conducted in an effort to bring forward the perspectives and academic lives of three independent scholars, Cal, Phinnia, and Ty. I turned to qualitative research for this part of the study because I wanted to know more about the experiences of independent scholars with disabilities (mental disabilities in particular), and I was unable to find published work that spoke directly to my questions. I came to my questions by way of the research that is described in the first chapters of this book. An academic’s job, I had concluded, involves the following actions: first, produce “work” (usually in written form); and second, gather in rooms (both classrooms and meeting rooms) with other people and talk about that work. But what if those seemingly simple requirements conflict with a person’s modes of communication, learning, and knowing? I couldn’t stop thinking about the statement from Clarice, a faculty member with Asperger’s, quoted in chapter 3: “A meeting can be a disaster for someone on the spectrum” (Avinger, Croake, and Miller 211). With this in mind, I formulated three research questions:

1. How do independent scholars with mental disabilities<sup>6</sup> pursue academic work including writing, attending conferences, and networking with colleagues?
2. How do such persons construct their own positions in relation to academic institutions, including their own processes of self-naming and self-identifying?
3. What access barriers and benefits apply to persons with mental disabilities who pursue academic work?

I selected these three participants because I know their work well—both published and unpublished—and all three met my definition as independent scholars with mental disabilities. Importantly, as the study unfolded, it became clear that Phinnia, Ty, and Cal do not necessarily define *themselves* this way. Their own self-identifications are discussed below. This is an exploratory study, using a convenience sample, and is therefore limited. Future research projects will, I hope, address larger numbers of in-

dependent scholars with disabilities, using a variety of methods. My purpose at present is simply to open the arena, to offer suggestive questions for further investigation, and to relate these stories.

One of my primary concerns was how to conduct ethical and effective research with participants who occupy positions vis-à-vis academe quite different from my own; who have mental disabilities; and who are my friends. The issues I raise here are indebted to the work of feminist and DS researchers including Colin Barnes, Tim Booth, Michelle Fine, Gesa Kirsch, Patti Lather, and Mike Oliver. During the study, I attempted to adhere to an *interdependent qualitative research paradigm*—one in which the progress of research relies upon participants and continually seeks their feedback and guidance. To some degree, this is simply a way to name what has always been true in qualitative research: the researcher needs participants, and is dependent upon them, even as her power as interpreter and writer of findings is an ongoing problematic. Further than this, however, I believe that acting as an interdependent researcher, especially within a DS framework, should involve taking risks and operating in unfamiliar modalities. The usual model of qualitative research assumes that the “design” will be set ahead of time and that any responses that do not conform to the requirements of that design are unusable—in some disciplines, are “tainted” data. By contrast, an interdependent qualitative research paradigm suggests that the site of such “taint” is in fact where the action is: this is where questions arise, where researcher and participant must communicate, where compromises take place and participants’ decisions will guide and even redirect the course of a study.

I knew from prior experience that all three participants had written at some length about their lives, including their disabilities, and in some cases treated the subject with casualness and humor. For example, one of the tags on Phinnia’s blog is *my head is pasted on crooked yay*, used to mark entries in which she records her experiences with anxiety, medications, brain fog, and other issues having to do with her emotional state. But the reason I know this is not because I conducted any sort of “objective” scan of LiveJournal blogs; rather, I know it because she is my friend. This study applies what Lisa Tillmann-Healy has called “friendship as method,” which involves “conversation, everyday involvement, compassion, giving, and vulnerability” (734). Friendship as method, Tillmann-Healy explains, involves increased risk for both participants and researcher(s) because, in their dual roles, all experience heightened levels of

vulnerability (741, 743). An example of the complication this added to the present study was my concern about inadvertently revealing information that had been given to me “as a friend” but not “as a researcher.” Over the years of our friendships, I have become privy to quite a bit of information about the participants through channels such as personal emails and password-protected blog entries. It would not be ethical, of course, to use such protected information without explicit consent. And yet that sort of information does not necessarily come in separable units. My knowledge of Phinnia’s battles with public transportation, of Cal’s frustrating history with the DS community, of Ty’s familial losses—this knowledge infuses what I write about them and how I interpret their words, whether I refer to it directly or not. Complicating the situation still further is that sometimes, during the course of the study, participants would reveal information and then add a note such as “I’m not sure if I want you to put that in or not.” In other words, *because* we were conversing as friends, we were divulging information that might or might not be appropriate for inclusion in a publicly presented study. As Carolyn Ellis has written, when conducting research with friends and other intimate acquaintances, “there is no leaving the field” (“Telling” 13). Because of these concerns, Tillmann-Healy argues that friendship as method “all but demands that writings be taken back to the community for examination, critique, and further dialogue” (744). I agree with this point, and would add that DS methodology places a similar imperative upon its researchers: if we are truly dedicated to “changing the social relations of research production” (Oliver), we must place co-interpretation at the center of our work.

I take the term *co-interpretation* from Thomas Newkirk’s “Seduction and Betrayal in Qualitative Research.” Newkirk’s vision of how to “share” work with participants is especially useful for DS methodology, because it emphasizes *ongoing* discussion of data rather than simply mailing out a manuscript after data have been collected, analyzed, and written up. Newkirk argues that participants should have access to a researcher’s emerging interpretations so that they can offer their own interpretations or “mitigating information” (13). In the present study, because participants’ stated preferences were for online rather than face-to-face interviews, we had the luxury of time during which we could reconsider questions, pose counterquestions, clarify our ideas, and offer further information. It also provided the space for me to share other pieces of the book with them, including the project proposal, individual chapters, and

emerging versions of this chapter. But the approach had a limitation as well, one that participants pointed out to me, and that I plan to change the next time I conduct a similar study: Ty, Phinnia, and Cal were isolated from each other during the data-collection stages. Because of concerns about confidentiality, I was careful not to reveal participants' identities to one another as interviews began; and even after each gave his or her permission to be named, I still didn't share their interview comments. In short, they didn't really "meet" one another until they received the common email that included my first tentative draft of the chapter. A fully co-interpretive approach, I believe, would rectify this problem by introducing group as well as individual interview opportunities. This would be easy to set up online, through a commonly accessible blog, "chat" space, or shared emails.

My caution about confidentiality, I think, was a symptom of my ongoing anxiety about the risks that friendship-as-method entails. Despite the study's layers of "mitigating information" (Newkirk 13), I still felt nervous about my choice of design; I was also strongly aware that mental disability is a highly charged topic, and talking about one's mental disabilities in almost any context involves considerable risk. Therefore, I made an early decision about one aspect of my approach to co-interpretation: anything a participant wanted to have removed from the chapter would be removed, without question. This promise was stated on each informed-consent form and routinely referred to throughout the study. Although in some cases qualitative researchers may choose to retain contested information in a final write-up since "we owe readers an account that is as comprehensive and complex as possible" (Tillmann-Healy 741), and in other cases may look for middle-ground choices such as noting a participant's concerns but still including the contested information, I decided that in this case I wanted to draw a firmer line.

As the interviews began, I held email conversations with each participant to explain my hopes for a co-interpretive exchange. For instance, I wrote to Ty:

[I'd like to] set it up as a highly collaborative research project, with due credit to you written into the chapter's explanation of the approach. As in, I share my thinking with you (which includes you reading the ms. in progress, if you can stand it), and then we together decide how best to present your "case" as an independent scholar. We could structure it as a series of conversations (email

and perhaps some in person, but it's critical of course that whatever methods we use follow best-access for you), maybe posing questions back and forth, etc. I'd really like it to be more dialogic, in other words, than "HERE IS THE CASE OF TYLER (NOT HIS REAL NAME)."

This aim, in my estimation, was largely successful, and participants affirmed my sense of its success. However, it also introduced yet another complication: the problem of *structure*. Early in our exchanges, Cal wrote to me, "I guess what makes me uncomfortable about this whole thing is that it doesn't seem very structured. I tend to need guidance in ways that most other people don't, and I end up completely confused about what I am supposed to do." In other words, through my efforts to create a co-interpretive environment, I had unwittingly set up a situation that was not accessible for her. In that case, I revised my approach by creating a list of questions, which I sent along—at Cal's request—a few at a time.

Cal's point about lack of structure guided my later exchanges with Ty and Phinnia. For example, when Ty and I began our conversations on email, I mentioned that we might also use LiveJournal as our medium, which would offer the advantage of "threading" each topic so that it would occupy a visually discrete space. Ty initially refused this suggestion. However, as our conversations progressed, email became less and less accessible for him. He wrote:

Re: your chapter, I keep thinking about it and I do want to get back to it and I'm not sure that picking up email is going to be the best way just because email sometimes feels way overwhelming. (My inbox today, from the last few days, had 700+ messages . . . even though most were "junk" and many were not important, when I approach email with the idea of "check email, get back to Margaret, etc" I often don't get *through* the check email phase.) So maybe we *should* try private LJ posts or doing something like a Google doc. The idea of making you juggle different strands of conversation in different formats makes my head hurt, though, so let me know what will not make *your* head hurt :)

Accordingly, Ty and I moved our conversation to LiveJournal, where I set up a space that was accessible only to the two of us, and where we con-

ducted a threaded conversation—again, over time—using the site’s “Comment” feature.

The question of structure is intertwined with another methodological issue that I became increasingly aware of as the study progressed: *time*. Tillmann-Healy notes that studies using friendship as method must progress “at the natural pace of friendship” (734); this turned out to be true of the present study, and its pace was further affected because it unfolded in “crip time.” In conventional interview studies, the researcher controls the amount of time to be invested by making decisions about the mode of interviewing (face-to-face, telephone, or online), how many questions will be asked, and how much time each participant will invest. In fact, some institutional review boards (IRBs) recommend that such decisions be announced ahead of time so that participants can be informed of how long their investment in the study will last. However, since I was attempting to use a more flexible methodology, I had no such guidelines to offer participants. Instead, I asked them to tell me how they wanted the interviews to unfold. I began by offering a choice of modes: face-to-face in person; by telephone; or online. All three participants chose the online option, but in quite different ways. Cal determined that she would prefer to receive the questions by email in short batches, three or four at a time; Phinnia asked for the questions by email, but all at once; and Ty determined, after some efforts on email, that a blog format would work better. Sometimes a month or more would go by before I received a response to an email I had sent. Periodically I would check in with participants, but I was hesitant to do so too often: they were working within constraints that included pain, brain fog, family obligations, anxiety, and work schedules. This is a situation in which my own mental disabilities offered an advantage. I know from experience that anxiety, pain, and fatigue can create a highly idiosyncratic work schedule, and that periodic “reminders” may be helpful, but that respect for the needs of one’s own bodymind must be paramount. I also know from experience that people with mental disabilities rarely, if ever, receive sufficient recognition for the tremendous effort involved in carrying out what most people consider “everyday” tasks, and I included frequent acknowledgments of this in my responses to participants.

All these efforts were a part of a complicated exchange of encouragement, insight, and affirmation that formed this study’s approach to reciprocity. Reciprocity is always intertwined with the issue of time to some

extent, for the currency of exchange in qualitative studies is often measured in chronological terms: participants will invest  $x$  amount of time and will receive  $y$  in exchange. Sometimes the compensation is a small amount of money; sometimes it is a service offered by the researcher, such as free tutoring; sometimes it is as simple as an expression of thanks. In the present study, I attempted to compensate participants in ways that seemed in keeping with the approach of “friendship as method.” I sent Cal and Ty each a book, and Phinnia requested a pair of hand-knitted socks.

In one sense, I am studying my peer group: we all have mental disabilities; all of us are white; and all of us are queer.<sup>7</sup> But in another sense, I am “studying down” (Fine; see also Kirsch), because I have a tenure-track job, and I am privileged in ways that make it easier for me to access academic spaces than for the study’s other participants. I am the only one who can log on to a university website and request any book or article I wish through interlibrary loan, and the only one whose travel to conferences is subsidized by my employer. While Phinnia, Ty, and Cal can and do access materials and conferences through various means, it’s important to mark the *ease*—that is, the privilege—of my own access. In part for this reason, I chose to practice a form of reciprocity that Tillmann-Healy calls “radical reciprocity,” in which “we never ask more of participants than we are willing to give” (735). My practice of “radical reciprocity” included offering information about my own experiences of mental disability, both to participants during our interviews, and in the write-up of the study itself. I also offered to provide any books or PDFs they might need that related to their work on this chapter. Because I have the privilege of a tenure-track job, I am not classifying myself with them as an independent scholar. Rather, I am attempting to align myself with them in terms of other issues—particularly mental disability—in a move of solidarity. To return to Nagel’s term, I am trying to gaze from *some-where* rather than *nowhere*. At the same time, I want to center the participants’ experiences rather than my own—for one danger of self-reflexivity is that it “risks turning representation into a solipsistic, rhetorical position in which the researcher (the self)—ah, once again—usurps the position of the subject (the other)” (Brueggemann, “Still-Life” 19).

To their words, then. After a brief introductory sketch describing each participant, the following sections are divided thematically. I relied on participants to help me determine the plausibility and integrity of each theme. When sending them a draft of the chapter in which I had assigned tentative categories to the data, I asked them to question the categories



themselves, opening the possibility that my analysis might need to be reshaped according to their interpretations of the data. Although none chose to refigure the themes themselves, their comments in our subsequent exchanges considerably changed the content of each theme's discussion. The themes are

- Disability, impairment, and diagnosis
- Identifying as a scholar
- Isolation and community<sup>8</sup>

### Sketch of Each Participant

Phinnia is thirty-two (“as old as my tongue and a little bit older than my teeth”). She lives in the Pacific Northwest with her husband and son; she also has two girlfriends, with whom she communicates daily online. She is a prolific blogger, posting anywhere from 250 to 3,000 words a day on topics including her fiction and poetry writing, her participation in other online communities, and her everyday activities. Everyday activities include working with her seven-year-old son, who is blind, autistic, and nonverbal, and advocating for and with him in his school and after-school environments. They also include wrangling rides for herself and her family on systems of transportation she has dubbed “failtransit.” Phinnia uses a wheelchair and experiences severe joint and muscular pain; daily events around these topics are tagged on her blog with descriptors such as *medical-go-round* and *mind vs. body smackdown*. She regularly takes part in community writing events, both online and face-to-face, and has published her writing in journals including *Breath & Shadow* and *Electric Mandolin*. She identifies herself as a “self-historian” in reference to her nonfictional writing, and as a poet and short-fiction writer.

Ty, thirty-eight, lives in semirural New England with his partner and two sons. A transsexual FTM (female to male), he has published work in a wide range of venues, including the anthology *Pinned Down by Pronouns*. While working as a writer for a large educational publishing company, he created many research-based presentations on topics ranging from HIV prevention to pedestrian safety. He is a founding member of Al-Fatiha, an organization for LGBTQ Muslims, and has also been cochair and keynote speaker for True Spirit, the annual conference of American Boyz.<sup>9</sup> Ty is hearing-impaired, adding, “The term ‘hearing im-

paired' is problematic because the Deaf community is often unwillingly included under its umbrella; however, I feel that for those with partial hearing it is preferable to 'hard-of-hearing,' which carries an implication that hearing is 'hard' (i.e., requires effort) rather than impossible for people with hearing limitations." He does extensive organizing and teaching work for his local Unitarian Universalist congregation, and is hoping to continue his graduate studies in communication.

Cal, forty-two, lives in the Midwest with a roommate and two dogs, Nate and Murdo. She has written for journals including *Ragged Edge Online*, and has presented at conferences including Autreat, the American Association of Philosophy Teachers, the Radical Philosophy Association, and Society for Disability Studies and, using a reader, has had her work presented at a Queer Disability conference. Her original academic training is in philosophy but she was "derailed," first by long-term institutionalization and later by access problems. Following a period in which she was unable to work, she is currently undertaking an independent course of study based on "all the things that I would have learned if I were going to school in disability studies (and if I had designed the program) before—I hope—returning to the fray."

### Disability, Impairment, and Diagnosis

I specified from the beginning of the project—in the study's introductory letter and consent form, as well as during interviews—that two of the study's grounding terms (*independent scholar* and *mental disability*) are ones I bring to it, and I asked participants to talk to me about their own processes of self-naming and self-identifying. In reference to *mental disability*, all three participants expressed understanding of the reasons why I use this term, but chose to identify themselves in other ways. Phinnia, for instance, wrote:

*Mentally disabled* to me implies a cognitive component, which doesn't really apply in my case. . . . I'd prefer to call myself "emotionally disabled" because it's closer to my self-concept: my emotions (fear, anxiety, depression, panic, etcetera) are really my disabling condition.

When I first began the process of interviewing, I was using the term *psychosocial disability* more often than *mental disability*, and Cal mentioned

at one point that she thought the former term was a better descriptor. She wrote,

I had the impression that you were using “psychosocially disabled” to include the people I consider to have “cognitive impairments” as well as those I’ve considered to have “sensory impairments,” which is one of the things I liked about it.

Cal’s use of *impairment* is a deliberate choice. She is cautious with the term *disability*, explaining: “I do not say that ‘I have a disability’ because to me that would be like a black person in a white-dominated society saying ‘I have a racism.’” In her view, the U.S. social model of disability (or rather, the many views that claim to be “social model”) tends to place the responsibility for lack of access upon individuals—even when claiming not to. Her language use, she explained, draws more from the British social model, in which “‘impaired’ has to do with inherent limitations, while ‘disabled’ has to do with socially imposed disadvantages that are neither caused nor justified by impairment. . . . In American thinking I don’t tend to think the language really exists to make that distinction, which I think is vital.” This is a point on which we differ; to my mind, “having a mental disability” does indicate disadvantages that are socially imposed rather than inherent. However, Cal’s interpretation of my thinking—that it seemed more “American social model” than “British social model”—made me newly aware of how slippery distinctions of language can be, even in conversation between two people with apparently similar frames of reference. Particularly when conversing with Americans, Cal noted, “I use other phrasing to make it clear which of the many definitions of ‘disability’ that are out there I’m using.” These include *disability-ASM* (American social model), *disability-BSM* (British social model), *disability-ADA/504* (Americans with Disabilities Act and section 504 of the Rehabilitation Act), and *disability-Amundson* (in reference to the work of Ron Amundson).

Cal later elaborated, “I do think we need a way of talking inclusively about people for whom *access to human interaction* is problematic” (emphasis added).<sup>10</sup> This point also emerged, although differently charged, in Ty’s description of his disabilities. In Ty’s case, his hearing (a “physical” or “sensory” disability) can operate causally to produce emotional effects:

I definitely see my hearing as something that interacts with my anxiety. [For example], when I was in high school, I found out that

on a day I was absent from math class, one of the students said, “Well it doesn’t matter anyway, because she’s not here even when she *is* here.” Which I think had a lot to do with how much I missed because I didn’t hear. But it definitely triggered anxiety . . . I sure didn’t want to go back to class after that, definitely didn’t want to ask questions or volunteer answers in class if they might be redundant, etc.

What I draw from these comments is that, although the participants identify in various ways, all three prefer to name themselves *in context* rather than abstractly. One of my interview questions asked, “Does [the term *mental disability*] feel like it applies to you? Why or why not?” and—in that acontextual format—the question didn’t draw much response. On the other hand, as they were answering other questions about their work and their lives, Ty, Cal, and Phinnia made frequent references to their impairments or disabilities as a means to clarifying specific situations. An example of identification in context is Cal’s choice to claim the label *crazy*, saying that, after years of institutionalization, forced medication, and ECT (electroshock) therapy, she feels she has “earned the right” to this label, although she has been urged by family members not to use it.

My question about the applicability of the term *mental disability* was not intended to be diagnostic, but it has some features in common with medical diagnosis—notably, its suggestion that it might provide a generalizable “truth” absent of context—which, I believe, is one reason participants rejected it. All three participants are familiar with the discursive and often oppressive nature of diagnosis. As a group, they have been diagnosed, at various times, with “disorders” including anxiety, depression, autism, multiple personality disorder (MPD), post-traumatic stress disorder (PTSD), bipolar disorder, catatonic schizophrenia, obsessive-compulsive disorder (OCD), and attention-deficit hyperactivity disorder (AD/HD). I am presenting their diagnoses in a group in an attempt to disrupt the medical and individualistic model of disability that would suggest that we ought to try to match different people’s ways of learning and knowing to their diagnoses in a deterministic way. Although each participant refers to his or her diagnoses at various times, and in some cases chooses to claim one or another, this is not the most important information about them, and is more usefully considered as part of the rhetorical web within which they operate rather than as a set of labels that might determine some “truth” about them. For instance, Cal stated, “I really

try to de-emphasize my diagnoses when I write,” and explained her decision this way:

I think that people [general readers] really want to read things by someone like me that explore my personal experience, and they don't consider that I can have anything to say other than personal experience, and that even if I did it would not be appropriate for me to do anything other than “interpret” autism for parents and professionals. But many people are open with their labels, or they are easily identified by others as having impairments that those others connect to decreased intellectual potential, and they are systematically not taken seriously by the people who read their work.

Here, Cal identifies one of the problems with being labeled, even by oneself. If the label is stereotypically considered to attach to “decreased intellectual potential”—as is true of most mental-disability diagnoses—then readers will tend to assume that the author's work is merely anecdotal, of little scholarly or analytic value. This observation testifies to the influence of the personal/critical divide that persists in academic discourse, with an added twist by way of mental disability: if one is seen as having “decreased intellectual potential,” then one's writing must be *only* personal, or *merely* personal, rather than a critical commentary. Thus, Cal's published writing often sets aside the question of self-labeling. For example, the bio attached to her acclaimed article “Critic of the Dawn” reads simply, “Cal Montgomery is an activist, writer, and speaker focusing on disability issues.”

Despite their awareness of the problems posed by diagnosis, all of the participants expressed an attendant awareness of its importance in their material lives—in particular, its relevance to the medications and quality of care they can access. For example, Phinnia celebrated the arrival of a pain-related diagnosis with the blog-entry title “can has diagnosis nao YAY.”<sup>11</sup> Although chronic pain is often identified as a “physical” rather than a “mental” disability, it has many important ties to my broad definition of mental disability, especially since health-care practitioners tend to treat people reporting pain with suspicion. The common stereotype is that pain conditions are “all in the head” and that a person seeking pain medication “just wants the drugs” (i.e., is an addict). As a result, adequate pain diagnoses can be extremely hard to obtain, and the search for such a diagnosis may be taken by medical practitioners as an indication

of mental disorder. Cal remarked on a similar diagnostic battle, one that resulted, like Phinnia's, in a potentially useful diagnosis and treatment: "This summer I finally got my pain specialist to take me seriously, and I am now on a drug that is seriously debilitating—a lot of the time I am awake for maybe three hours a day and I am having nausea and so forth—but that is worth it to me because I can once again read." Only rarely did participants self-identify by means of diagnostic labels; however, all are well aware of the material importance of diagnosis in their lives.

### Identifying as a Scholar

The question of how they might identify in relation to the term *independent scholar* seemed to engage participants more than the question of identifying their disabilities or impairments. The Gross and Gross definition, discussed above, which suggests that an independent scholar should pursue "serious, intellectual inquiries outside academe, resulting in findings that have been accepted by fellow scholars as significant contributions" (2) was addressed at length. Ty's response to it focused on the problem of *audience*:

In reading that definition, it seems to be validating independent scholarship by virtue of its acceptance as valuable to other scholars. A number of flaws in that definition jump out at me. For one, the expectation that an independent scholar's work will result in "findings" to be evaluated by others seems to be assuming that independent scholars have the same access to research funding, publication and presentation options (e.g. at conferences) as those who have ties to academe. How else would other scholars have access to their ideas to validate and accept them? I am sure there are "independent scholars" (such as those who work or volunteer for non-profits or lobby groups) whose work does allow them to conduct studies and publish findings, but to require that as a criterion seems to exclude the vast majority of non-academic scholars who might have valuable contributions to make.

Another issue is that other scholars who accept and value an independent scholar's contribution may be, themselves, unattached to or alienated from academe. Would their acceptance "count"? This also brings us back to the first issue: if an independent scholar

accepts another's work as valuable, that acceptance may not be presented in traditional scholastic ways, due to lack of access to publication.

Here, Ty points out the paradox raised by the Gross and Gross definition. If an independent scholar is to produce work that is "accepted" as "significant" by fellow scholars, that scholar must be able to *get* his or her work to an audience of fellow scholars. Yet the access barriers that accompany life as an independent scholar—for instance, as Ty mentions, having little or no access to research funding or conferences—makes it much more difficult to locate and reach that audience.

Moreover, as Ty points out, alternative audiences, such as those who attend community-organizing conferences or who operate mostly through public online communities, may be devalued. He offered an extended example of his work with several community-organizing groups and questioned how that work might "merit the label 'independent scholarship'" according to the Gross and Gross definition.

I was a founding member of Al-Fatiha and, in 1998, was one of four people who were part of the first face-to-face meeting the group ever had (it was started and grew online, a fact which allowed it to become an international network for a very geographically-scattered population). From the beginning, I posted frequently about topics relating to gender identity and feminism, as well as about religious and spiritual practice. As the online group grew into a grassroots organization, the founder, Faisal Alam, appointed a shura (advisory board), of which I was a member until it was replaced by a Board of Directors. . . . At the second Al-Fatiha conference, in 1999 in New York City, I co-presented on gender identity and its relevance to the larger LGBT Muslim population. My co-presenter, Faris Malik . . . held a Master's degree in German literature, so it could be argued that he had some academic background; however, that did not provide a basis for validating his perspective on a topic so far removed from his academic field. Likewise, my own Master's degree in Mass Communication did not give me academic credentials to justify my presentation about Islam and gender identity. Still, it could be argued that in the area of LGBT Muslim issues, Malik and I were both knowledgeable, contributed new perspectives, presented our ideas and were ac-

cepted by each other, at the least, and by the conference attendees. Some of the attendees could also be considered knowledgeable and have written and presented on LGBT Muslim topics themselves; however, to my knowledge, only one has ties to academe.

Does this merit the label “independent scholarship”? Using the Gross and Gross definition, probably not. There is no record of any “acceptance” the attendees may have conferred upon Malik or me, or any that we conveyed upon each other. Even if there were a record of the “acceptance” of our work, an argument has to be made for the scholarship of the attendees in order for that “acceptance” to carry any weight. Had I presented at an established academic conference about Islam, religion, gender, or queer studies, there would be validation of my work with Al-Fatiha as scholarship of some sort. Yet it was highly unlikely that an established academic conference would invite a non-academically credentialed individual to present in the first place.

Through this example, Ty illustrates what it means to exist at the margins of an academic system whose system of reward tends to operate through a process sometimes called “logrolling.” Even systems such as anonymous peer review, which is supposed to be one of the main tools used by academe to maintain the integrity of scholarship, can be influenced by “personal friendships or animosities and desires to curry favor” (Rhode 58). To put it simply, in the current academic system, the rich get richer. This is not a new observation; however, it is rarely noted in reference to independent scholars with disabilities, whose intersectional positions are met by multiple and sometimes unique barriers.

Cal’s take on *independent scholar* was similar to Ty’s in her emphasis on the problematics of “acceptance” and audience. She wrote:

I have a real problem with the idea that findings have to be accepted by fellow scholars as significant. I think peer review is to a great extent the way that we know whether someone is a scholar, especially in fields like disability studies where people have such diverse backgrounds and so few people are really qualified to judge a given individual’s work. . . . I would consider a scholar someone who engages with a reasonably current (depending on the field) group of scholars, whether they are taking the significant contributions of others and working on them in a way that their peers would be



willing to consider a significant contribution if the work were presented to the peers in a neutral way so that it could be considered without prejudice, or whether they are making contributions to which other scholars are responding. But I wouldn't consider that someone who is frozen out by academics who are operating from prejudice would be a non-scholar, even though people from other disciplines might not be able to tell that they are a scholar.

Here, Cal's argument is much like Ty's: that is, while there must be some set of common ways to measure the value of scholarly contributions, a definition that turns on "acceptance" ignores—in fact, conceals—the problem of access. She added that the access problem might extend to ways that people with certain kinds of disabilities are viewed before their work is even considered: for example, "I am regularly informed that people with IQ scores below 85 . . . cannot possibly benefit from postsecondary education and ought to be excluded from even open-enrollment schools." The absurdity of this suggestion is belied by Cal's own history: although her IQ was once measured (while she was institutionalized) and recorded as 80, she had a highly successful undergraduate career, was accepted to competitive graduate schools, and studied and taught successfully in graduate school for three years. Access barriers did influence her decision to leave grad school after three years, but it's obvious that the problem was not her "intelligence."

Unlike Cal and Ty, Phinnia does not identify any of her work as scholarly. Calling herself a "self-historian," she explained:

"Scholar" to me implies a research focus. (For example in the term "scholarly article," which implies something in an academic journal setting, frequently peer reviewed.) My work is better classed as either fiction or autobiography (depending on the setting), and although [the latter] often blossoms from research, it's more subtly applied there, and [in the former case] doesn't apply at all, because it's coming from a personal space. Scholarly to me implies non-fiction.

Phinnia's definition of scholarship is therefore most in line with conventional academic definitions: "scholarship" is work that appears in academic journals and does not come from "a personal space." Although "personal"—even "fictional"—and "scholarly" work can intermingle in

some contexts,<sup>12</sup> this is not the case in Phinnia's work. In fact, as our conversations continued to unfold, it became clear that defining her writing—both fictional and nonfictional—against “scholarly research” is a point of strength for her, as it affords her greater freedom of choice in genres and publication venues.

Phinnia's point that personal narrative operates differently from conventional scholarly research is certainly true from a practical standpoint: works such as Carolyn Ellis's “evocative autoethnography” or Kathleen Stewart's “cultural poesis” are the exception rather than the rule in academic discourse. Moreover, as Ellis herself has pointed out, the pressures of the academic reward system may discourage scholars in less-established positions from working in experimental or genre-bending forms. In “Evocative Autoethnography,” Ellis looks back at the realist-ethnographic approach she took in her first book, *Fisher Folk*, and explains, “In 1979, I didn't wonder why sociology, my chosen discipline, couldn't be written more like a Tolstoy story; I couldn't afford to. I had a dissertation on fishing communities to finish, then a book to publish, then a tenure review to pass” (116–17). The pressure of being an “aspiring academic” (Gappa and Leslie) may therefore be seen as limiting: as Phinnia noted, “I have a certain amount of personal and academic freedom that I enjoy given that I report to no one.” A similar advantage was noted by Ty: “I have the opportunity to screw up without a lot of people noticing, and without worrying about my professional reputation.” However, he also made it clear that, from his perspective, this is “the only major plus” of working outside the privileged reaches of academic discourse.

Phinnia's take on academic and writerly freedom is heavily influenced by her awareness of the limitations that editors, journals, and even genres themselves can place upon one's writing. In a follow-up comment to my question “What feels most important about your written or scholarly work?” she emphasized the importance of “pleas[ing] myself” above other priorities.

I write everything for myself first (even the things I write for other people are written in a format to please myself). I think that's an important distinction to make, because it contributes to something else I've mentioned, the fact that I'm not “responsible” to anyone else. It's something I'm struggling with about publishing, because publishing often requires you to write to a certain spec and I'm trying to figure out how far I want to take that. To a word length is

one thing, but writing content is an entirely different animal. I have a lot of anxieties when it comes to editors and agents potentially changing things radically to make things “saleable.” I’m not meaning that in a “my work is all perfect” sort of way, but I do know that the demands of the “market” are often way different than my own “tastes.” The best example I can find is when they make a movie out of something and it’s been cut to ribbons? I don’t want that to happen to me. I wouldn’t be able to respect myself. So that’s a big hurdle I have to clear, undoing the association between “professional publishing” and “tearing things apart.”

In this statement, Phinnia foregrounds a concern shared by many academic and creative writers: the problem of making one’s own perspective “saleable” for the marketplace. Perhaps for this reason, Phinnia’s marketplace is decidedly alternative: she publishes in new genres including fan fiction and flash fiction;<sup>13</sup> her poetry appears in small journals; and she generally does not aim for more conventional commercial or scholarly audiences. This decision complicates the suggestion from Gross and Gross that an independent scholar’s work ought to be “accepted” by fellow scholars. Phinnia’s work is indeed accepted, and enthusiastically; every piece of writing she publishes receives a torrent of admiring commentary on her blog. But she has chosen to build her own community of readers rather than attempt to conform to the more established (and more ableist) community of conventional academic and creative work.

### Isolation and Community

The double-edged nature of scholarly freedom/isolation has received considerable commentary in writing about independent scholarship (Bell, “Independent Scholarship”; Sonenschein). Of the three participants, Phinnia seems to access most comfortably the writerly community of which she wants to be a part. For example, she is a member of numerous Internet communities devoted to her chosen genres; she also regularly takes part in community writing events near her home. This may be due, in part, to the fact that she identifies herself more as a creative writer than as a scholarly writer, and that communities for writers of her chosen genres have recently proliferated. By contrast, both Ty and Cal discussed at some length the barriers they have experienced in attempting to access conversations with like-minded academics.

For Cal, two spaces that present significant access barriers are classrooms and conferences. Reflecting on her experience in graduate school, she wrote, “I used to really enjoy the intellectual give-and-take you could get in an active academic department, but since becoming unable to speak I’ve found it much harder to participate in that sort of thing: other people can silence me simply by turning their heads, and most people seem to want to do that.” (She had earlier explained that her ability to speak had been intermittent for years and “finally shorted out” in 2001.) Moreover, she understands little of what is said to her in an oral/aural context. For these reasons, both classrooms and conferences are highly inaccessible to Cal, and she has had a number of frustrating experiences at conferences, even ones that make significant efforts to be widely accessible, including SDS and Autreat.

Cal made the further point that, if one’s “access to human interaction” is already problematic, this can set off a cascading reaction in which other forms of access become less and less possible:

Access to the contents of texts and the contents of lectures is a big one for me, and I believe for some other people. Yes, ADA/504 should protect us, but if we aren’t well-networked, we run into situations where we have to find a way to enforce our own rights, and we don’t always know how to do that. . . . Once we don’t have access to texts and lectures, we lose academic library access fairly quickly. (I would have library access if I went and pushed for it, but it’s unclear to me whether or how I would access interlibrary loan. Previously I had library access but no access to ILL.) . . . And because many of us are working in low-wage jobs or living on disability payments (note that when I say “many of us” I am including myself as a part of the larger “us,” but I am luckier than many people and can buy used books pretty regularly), creating our own libraries can be difficult. I’m very lucky there, just as I am lucky to have been able to read well enough to get by in my undergraduate years without really understanding lectures, so long as I was willing to turn to books to find out what was probably happening.

The cascading reaction Cal describes here begins with a single inaccessible environment—a classroom. If a person has a disability that makes speaking, listening, or being taken seriously problematic, virtually every classroom in the United States will present access barriers. And the next

step usually required (in practice if not by law) is that this person will have to advocate for his or her own accommodations—*despite* the fact that communication itself is the arena of difficulty. Whether the next event is flunking out, dropping out, or a more euphemistic turn of events (such as “being academically withdrawn” from an institution), academic library access then disappears. And, as Cal points out, since many people with disabilities are already living on little money, the ability to build community by obtaining books and articles, and attending conferences, is often unfeasible.

While it would seem that publicly available Internet groups and journals could help bridge some of these gaps—as has been true for Phinnia—there are multiple problems with trying to attend, as Cal put it, “the University of Google.” Most obviously, access to the Internet in the first place presents economic barriers. Even if one has reliable Internet access, much of the scholarship on the Internet is available only in password-protected spaces that require subscription. Subscriptions are available to individuals, but are extremely expensive; I think it’s safe to say that most people who access subscription-only academic journals do so via some form of institutional affiliation. Investigating further, we find that are subtler problems to online access as well. For example, Ty told this story about an Internet-based group he founded in 1999 called Iman (for lesbian, bisexual, and trans Muslims):

[Iman] was active in 1999–2001 and then kind of petered out because of the fact that Queernet—a site which hosted many of the GLBT email lists at that time—had a major crash and all list owners had to reset the lists from scratch. That meant that *many* groups ended very suddenly, including several of those crucial to my coming out. The Al-Fatiha “gaymuslims” list ended up moving to Yahoo groups, and others were added like “transmuslims,” which has totally changed the nature of the lists because they are not as well moderated now and end up being spammed often.

The situation Ty describes is one example of the way that “infrastructure,” in the sense used by Jeffrey Grabill, combines rhetorical and material effects to deny access. Once again, the rich get richer (or rather, the affiliated get even better affiliated)—in part because they (we) can rely on a level of consistency and safety in the materials and communities we access. If I am reading about Al-Fatiha in a scholarly database that includes

the journal *Culture, Health & Sexuality* (see Minwalla et al.), I can count pretty reliably on two things: first, the article will still be there tomorrow if I want to go back and read it again; and second, I will not be randomly spammed by hate speech.

Ty's discussion of academic isolation and community seems to reflect more emphasis on internal processes than Cal's. Because of his hearing, he can, like Cal, be silenced "simply by [other people] turning their heads." In Ty's case, however, another significant barrier is his sense of not having a "right" to speak in scholarly conversations. He wrote:

When I think of submitting an editorial or an article on a topic, I immediately feel that there is little to justify my taking up "space"—I can't formulate an author bio that says "X is a professor of — at —" or "X is director (or assistant director or other title) of — program/project at —." There's just "X has a lot of undocumented knowledge about this topic." Similarly, for me to blog about a topic, I'm addressing friends who aren't necessarily in the same field and who are probably not all that interested in why Shi'a Islam's support of sex changes is theoretically wonderful but in practice sometimes actually oppressive to women, gay men and transgender people; or a serious consideration of the effect of Facebook, Twitter and even blogging communities like LiveJournal, on composition (as opposed to writing). I could definitely write on those topics and cultivate an audience of like-minded independent and academic scholars, but that again gets into "what right do I have to present my views and perceptions as having merit beyond myself and friends who are hopefully inherently interested (to some extent) in what I think?"

From the way he describes this internal process, it's clear that Ty is not presenting a straightforward assertion that he doesn't have a right to speak in academic contexts. Rather, using scare quotes and other discursive markers, he is conducting an analysis of the feeling itself. As I have argued throughout this book, access is constructed through attitudes as well as physical structures. Attitudes may come directly from others, or may come from the imagined audience to, or for which, one composes. And if the audience Ty imagines is asking questions such as "What right do you have?" it's unsurprising that he feels reluctant to begin the process of inquiry. Throughout our interview, I was repeatedly struck by the fact

that Ty and I viewed his work—including work that would meet even the conservative definition of “scholarship” offered by Gross and Gross—quite differently. For example, at one point, when explaining why he doesn’t consider most of his writing scholarly, he said, “Most of my knowledge is derived from reading others’ work. I do, sometimes, take that a step further in synthesizing that information and posing (and trying to answer) new questions. Yet, ultimately, it feels less like building on others’ scholarship and more like simply knowing about it.” To me, the process Ty describes—reading others’ work, synthesizing it, raising and addressing questions that stem from it—is a textbook (so to speak) definition of scholarly writing. But the key word in his description, I believe, is *feel*: what I or anyone else thinks of his writing matters less than how he feels about it. And this feeling, in turn, sometimes prevents him from beginning potentially scholarly projects, such as editorials or articles.<sup>14</sup>

Interestingly, while Ty does not feel particularly welcome in traditional academic arenas, he does a great deal of work in community-building efforts that combine his skills in service, teaching, and research. His work with Al-Fatiha and True Spirit are two examples; in addition, at his local Unitarian Universalist (UU) congregation he carries out a great range of activities. These have included speaking on interfaith panels; presenting at Nehirim (a Jewish LGBT organization); doing teach-ins on Islam; and serving on many committees, including the UU’s new Committee on Gender and Sexual Identities. He is also one of the most active members of the Stonewall Center Speakers Bureau at UMass-Amherst. Ty commented that his work in these arenas feels, in some ways, “more important” than traditional academic work, in the sense that his audiences for such activities “will take the information I offer and use it on the ground, with people in real-life situations.” Although community organizing is a different endeavor than academic work, it is striking how similar Ty’s chosen responsibilities are to a conventional academic job: teaching, research, and service (and collegiality).

### A Way to Move: In/ter/dependent Scholarship

As I researched the history and present status of independent scholarship in the United States, I found myself reminded repeatedly of the tradition’s prestigious history and of the importance, for many in this group, of identifying *as* independent. For example, in “The Noble Legacy (and Present Eclipse) of Independent Scholarship,” Toni Vogel Carey notes the

“inessential role of the university” in the lives of thinkers including Pythagoras, Plato, Aristotle, Jesus, Galileo, Newton, Adam Smith, Jefferson, Darwin, and Einstein (8). And in “An Independent Scholar by Any Other Name,” Barbara Currier Bell suggests that the advantages accruing to professors emeriti might “sound familiar” to independent scholars, including (quoting from Richard Wentz) “speak[ing] to the designs of scholarship and education without fear of obsolescence, methodological ostracism, tenure reprisals, salary rebuffs, or other forms of political disdain” (3). Work by independent scholars does acknowledge a level of interdependence, and the existence of groups such as NCIS and CIS indicates that communal efforts are strongly valued. Yet *independent* retains a strong hold, for, as Mark Hinline puts it, otherwise an independent scholar may be considered “the poor cousin of the affiliated academic scholar” (qtd. in Bell, “An Independent Scholar” 3). It is reasonable that independent scholars wish to emphasize their strengths and advantages; this is a group that is undeniably undervalued in conventional academic discourse. Thus independent scholars *are* independent, and often fiercely so; as one independent scholar wrote in his or her response to Sonenschein’s survey, “I live in poverty as a result of insisting on doing things my way . . . Doing satisfying intellectual and creative work, however slim, seems to have required this total idiosyncrasy” (51).

However, I’m concerned about the way that disability—and more to the point, conversations about access—may interact with this insistence on “independence.” My concern stems in part from the lack of conversation about disability in studies like Sonenschein’s 2004 survey: thus far, disability simply does not seem to be on the radar of organized associations of independent scholars. Indeed, the urge to maintain “independence” at times produces direct disavowals of disability. Quoted in Gross and Gross’s 1983 study *Independent Scholarship: Promise, Problems, and Prospects*, psychologist Rachel Lauer has this to say:

I suggest that you [the study authors] avoid any thought or language that creates the image of independent scholars as needy people whose interests must be served by others who are richer or more powerful. For example, I do not like to think of independent scholars as a “lost generation,” “wasted people,” “embittered, unemployable intellectuals,” “human tragedy,” “suffering from severe handicaps,” “displaced,” “unplaceable,” “discriminated against,” “unable to get or hold a position in academia,” etc. I do



not like for us to see ourselves as one more minority group victimized by the establishment, outsiders looking in, unappreciated and needy, disadvantaged, etc. I do not want to be part of a group, much less identified with a group, which must be “helped, supported, encouraged, recognized, served” by charitable others. As a psychologist in a “helping profession,” I have seen far too much damage—dependency, apathy, self-pity, inertia, paranoia, etc.—created by a helper-helpee reciprocity. (34)

In this comment, Lauer acknowledges the marginality of independent scholars, indicating that they are not the “richer or more powerful” members of the academic community. But then the statement quickly moves to conflate this marginality with dependency, and dependency with charity. Lauer’s concern about being seen as part of a “displaced” or “unplaceable” group uses repeated metaphors of disability (“handicap,” “paranoia”) as well as terms often used to devalue disabled people (“embittered,” “tragedy,” “needy,” “self-pity”). In her passionate argument against treating independent scholars as “one more minority group victimized by the establishment,” Lauer assumes that marginalization must lead to dependency, and that dependency must be disabling.

However, her assumption rests upon a fallacy: that the counterpart to independence must be *de*-pendence, and that all dependence is disabling. In contrast to Lauer’s view, DS engages in active questioning of the concept of “independence,” often resisting this notion in favor of some version of interdependence. Tobin Siebers offers a helpful gloss on this perspective:

A focus on disability provides another perspective by representing human society not as a collection of autonomous beings, some of whom will lose their independence, but as a community of dependent frail bodies that rely on others for survival. Notice that dependence does not figure here as an individual character trait, as in the social contract model, but as a structural component of human society. . . . We depend on other human beings not only at those times when our capacities are diminished but each and every day, and even at those moments when we may be at the height of our physical and mental powers. (*Disability Theory* 182–83)

The essay in which this quote appears, “Disability and the Right to Have Rights,” argues for establishment of disability, or “the fragility of the

mind and body” (183), as the theoretical cornerstone of human rights. While Western liberal traditions of thought posit that humans ought to have rights because of their prowess as individuals—whether that prowess is framed as being a “rational” thinker (Aristotle 1098a) or a “good man skilled in speaking” (Quintilian) or as having a “self-reliant” and “private” heart (Emerson 259)—Siebers upends this deep-seated ideology to suggest that humans ought to have rights precisely because of our *lack* of wholeness, our fragilities, our very dependence upon one another.<sup>15</sup>

As Siebers and other DS scholars have argued, the counterpart to independence could well be understood as *inter*-dependence, and could be seen as enabling—even empowering.<sup>16</sup> Moreover—and more salient to the present study—Lauer’s stance on the rhetorical position of an independent scholar disavows the possibility that such scholars might be *systematically* denied access to full participation in academic spaces such as classrooms, conferences, or university presses. Here again, we see the rhetoric of “choice”: if one does not teach for pay, the assumption goes, one must have chosen not to do so. However, given the inaccessibility of teaching (and speaking, and writing) spaces available in academe, it becomes evident that avoidance of these spaces may be a survival strategy rather than a true choice. That is, it may be a “choice” only in the sense of Hobson’s choice—the refusal of an intolerable option.

Numerous calls for ways to revalue independent scholarship have come from both inside and outside academe. For example, in *The Independent Scholar*, Stephen Shapiro has proposed the formation of “micro-colleges,” institutions formed by small groups of independent scholars and run as nonprofits (47). In the *Chronicle of Higher Education*, Elizabeth Welt Trahan has called for foundations and professional organizations to include a category for independent scholars in their grant applications, and to include independent scholars on their review boards. Some professional organizations have responded to the calls. The Modern Language Association offers a book prize dedicated to works produced by independent scholars, and *Disability Studies Quarterly* recently established itself as one of the few fully open-access peer-reviewed journals. Other journals such as *Kairos* have been open-access from their beginning. I am heartened by these moves, but insist that much work remains to be done. This work must be an interdependent effort, coming from communities of independent scholars, academic institutions, and individuals who are not affiliated with organizations. In his final reflec-

tions on this chapter, Ty made a similar argument, in words more eloquent than I could muster:

When I finished reading, I was thinking about the fact that our (or at least my) lack of academic affiliation is a factor in participating in a study like this, where disability and challenges are being discussed frankly. It seems a little like the SSDI/SSI catch-22: if I were affiliated with a university, I'm not sure I'd be as willing to put vulnerable information about my challenges out there for public—especially professional peer—digestion. The availability of that information to academic employers and peers could (to use Cal's great semantic distinction) create a disability (i.e., an imposed barrier) out of a limitation. Yet it also seems crucial for this kind of information to be available so that accessibility can be improved.