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Time, Work, and Chronic Illness

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- [1] I'd like to discuss some ways in which our academic lives are advantageous to us, and how lucky many of us are; but I would also like to point out that we have much work to do if we are to preserve our (relatively) lucky status.
- [2] My own connection to disability is tenuous, and some might say dubious. As a long-term survivor of AIDS (now for more than twenty years), I wrote a chapter for the Lerner & Straus collection (Attinello 2006, 13–22) on fatigue and chronic illness in connection with music. As I stressed in that paper, I know that not everyone considers a long-term illness to be a disability, and I don't think of them as being quite the same, myself; nevertheless many governments (including that of the United Kingdom) define AIDS and other illnesses as disabilities in awarding benefits. So, at least in legal and political terms, there is something to talk about here.
- [3] In that context, I'd like to represent a point of view not just on AIDS, but all chronic illnesses—I'm thinking of multiple sclerosis and other conditions that create intermittent fatigue, as well as diseases like cancer, where both the disease and the treatment can create ongoing weakness and depression. I'd also include psychological conditions, such as bipolar and depressive disorders. What these very different conditions have in common is that they may—with the emphasis on may—make it difficult for people to fulfill normal workplace expectations: such difficulty may be intermittent, or permanent, or progressive, or static; but that difficulty can have a significant effect on working lives and careers.

 Let me make some cuts into the problem.

Cut I: From Oxford to Community College

- [4] Because we are academics, we are heir to a tradition of exceptionally flexible work situations: as a lecturer at a British research university, I don't have to show up at a particular time each day, I don't have to do all of my work in the office, and there are days when I'm not even expected to come in. Of course I have the scattered, complex burdens of preparing and teaching lectures and supervising students, of keeping my research going on several fronts, and of administering various programs and procedures (in fact, British academics often have far more administration than most North Americans—unfortunately). But flexible times and circumstances, not to mention vast stretches of time around Christmas, Easter, and in the summer months, make the whole very unlike wage slavery. I can strongly attest to the difference, as between 1977 and 1997 I worked at various forty-hour-a-week jobs; and the difference has become deeply important to me—I think that, even without a chronic illness, I would never again let a boss insist that I show up every day at 8:30.
- [5] Our habits reflect an earlier version of the intellectual vocation, when an Oxford don would potter through old buildings among beautiful lawns, chatting with colleagues, occasionally lecturing, and thinking vaguely about his three-volume

masterwork on the boll weevil. Of course, we live very differently than that don, with much more pressure and many more demands—but, at least in a research university, we do manage to defend ourselves against the restructuring of those demands into the equivalent of full-time office work. Unfortunately, not all universities are equal in this: in Britain, there is a huge difference between what are called pre-1992 and post-1992 universities—the latter were once called polytechnics. Post-92 schools are generally much more rigid in their demands; my friend Patrick, who teaches mathematics at the post-92 university next to my pre-92 one, has much longer contact hours than I do, and is required to be in his office for thirty-eight specified hours a week, for all but six weeks a year—and then is not allowed to go into his office at all for those six weeks.

[6] Now, aside from the fact that I hate the idea of having to work that way, I know that it would have been impossible for me to function on that basis over the past twenty years. I am very healthy now, and over the years have cancelled extremely few lectures, meetings, or appointments—fewer, in fact, than many of my supposedly normally healthy colleagues. However, I know that at times when I have been somewhat ill for months on end, or when I've started new medications with unpleasant side effects, if I had been required to show up daily at 9 am, I would have had to resign—either to "go on disability," as the phrase is, or more probably, considering my sojourns in between the support systems of different continents, to live in a refrigerator box under a bridge. More importantly, I know of several academic colleagues—some of them notable, productive, and even famous in our discipline—of whom the same is true: that, if they were held to the requirements of the modern white-collar job, they would now lack careers, work—possibly even their homes or their lives.

Cut 2: Confronting Reagan's Lawyer

[7] Of course, our situation as academics is unusual, especially these days. That miserable, repressive, mechanistic forty-hour work week was a product of American industrialization; at one time, Europeans regarded the concept with dismay, and even now it is rare for a continental working week to be more than thirty-five hours, with six weeks of vacation. However, because we tiresomely puritanical Americans managed to forge a cultural, even a moral, link between five eight-hour workdays each week—minus just two weeks of vacation each year—and bourgeois respectability, that model has become far too common all over the world. This worsened in the 1980s, in connection with Reaganite/Thatcherite values: the workaholic lawyer who slaves away for sixty hours a week has been enshrined as an ideal of ambitious success, and employers in many fields feel that extraordinary demands are a useful way to measure employee commitment (or, perhaps, to abuse it).

[8] We are, of course, professionals—like lawyers, like doctors: relatively independent, producing out of our educated intelligence, we push to be treated as such by our institutions. But we aren't expected to survive punishing hours, as are North American doctors (the hazing rituals of overwork for North American medical interns are regarded with horror by European medical professionals, and rightly so, as they also lead to errors and a lack of empathy for patients); and we aren't expected to be quite so desperately eager to please as a junior lawyer in a large and competitive firm. At one time I would have assumed that most people realized that the sixty-hour-or-more model was recently invented, bizarre, and dysfunctional; but, as we have seen from some of the newspaper editorials on the financial crisis of 2008–09, many financial professionals who were brought up with 1980s values know no others, and believe in them to this day.

Cut 3: The Swedish Model and the Old Professor

[9] Melinda Firth, head of clinical psychology at the Newcastle hospital and founder of an AIDS patient group that I managed for several years, has pointed out that these concerns are very current in social policy and the National Health Service. There is a metaphor linked to disability: most Scandinavian countries have far better building access than those in the UK; therefore people who in Britain would be "disabled" can do many more things without hindrance. Which means that a condition—a particular syndrome of legs, hands or eyes, or a chronic illness—can be redefined through more consciously supportive policies: it may not be a disability at all.

[10] This has spun out into an increasingly widespread discussion in certain countries and institutions: why can't we redefine our expectations of work (job, career, income, benefits, etc.) such that some people who might have been regarded as disabled are transformed into people with no disability? Of course, this isn't just about health conditions; it's a core issue for women who want children, both during and after pregnancy. Why can't work weeks be flexible, such that real needs are taken into account, and people in various circumstances can work to whatever extent is appropriate for them? Melinda pointed out that this is in line with an increasing need to start focusing on outcomes rather than inputs: it doesn't matter when employees show up in the morning, it matters what they do. It is fortunate that social scientists and some corporations are already considering this as a necessary development (Fraser 1992).

[11] I also want to point out that, in addition to the flexibility common in research universities, we already have a category that reflects these values: that is, the emeritus. In business, when people retire, they pack up and leave, usually gladly; but in academe a retiree who enjoys or is devoted to her work may keep an office, meet with students—and even lecture on occasion. The emeritus is both respected and allowed to engage in *work*; admittedly it's usually assumed that an emeritus had previously had a long and hard-working career, but I think there could be great value in developing a culture of respect, and differing expectations and systems, for all those others who can't or don't want to work what is problematically called "full time."

Cut 4: Ability and superability

[12] The central argument in our favor is our range of abilities: we teach, we write, we edit, we administer—and we do it all damned well. In institutions that are at least partly detached from that tiresome forty-hour model, colleagues do many things every day, and do them with skill, foresight, and creativity; as outcomes go, those sound pretty good to me. But we still don't really have a value system, or a rhetoric, that can easily *defend* these abilities: in common discourse, academics are often made to feel that we are getting away with something, that we are lazier and less valuable than those sixty-hour lawyers. We even conceal our shiftless schedules from people who have "regular" jobs, because we know they will become resentful or sardonic, and say foolish and pernicious things about not living in the "real world."

[13] I can't help comparing this with my colleague Vanessa Knights, who assertively managed a debilitating autoimmune condition until her death in 2007 at the age of thirty-seven. Vanessa took charge of a truly exceptional array of projects and daily work (in a language department that demanded much longer teaching hours than my department), partly to further her bid for a senior lectureship; after she achieved that position, she considered changing to half-time, which would have been appropriate for her deteriorating health, but she died before making that change. Her department and colleagues treated her condition with respect, and willingly negotiated when necessary, but I still feel that she suffered from a generalized institutional pressure to do ever more, for her students, her department, her career—and that her death came even sooner than it might have as a result.

[14] Of course, normal workloads and working hours for academics have shifted, several times, over the past few decades. It was evident to me when entering graduate school in the mid-eighties that my professors were already dismayed by the new demands made on them; and since then those have increased—differently, however, in different systems. When I taught in Hong Kong, some senior professors were being taken to task, for the first time since their careers began, for being unpublished; during my Australian sojourn, academics all over that country were disoriented by a new rise in administrative duties and workloads; and the UK has of course been among the worst in this context for more than twenty years. Naturally, some robust types thrive under the pressure—I know academics who teach and administer at post-92 workload levels, yet somehow manage to crank out articles, and even books—but it doesn't make sense to demand such superhumanity of everyone; for most of us a heavy workload damages our ability to think, write, and teach at a credible level of reflective consciousness.

Cut 5: Jobless

[15] Perhaps the future will justify us, even dramatically. Joanna Russ, in one of her novels set on a planet inhabited solely by women, included a satiric jab at this—after many pages of her heroine fleeing a dreadfully boring job only to be hunted down by merciless police, we are casually informed that the work week on this planet is sixteen hours long (Russ 1975). Perhaps more contemporary is Aronowitz and DiFazio's *The Jobless Future: Sci-Tech and the Dogma of Work* (Aronowitz and DiFazio 1994). The authors tell us that, in an increasingly computerized society, there will be fewer and fewer jobs; and that means we need to stop tying financial security, as well as respectability, to the workplace. They claim that we are already beginning to need a very different model of life, work, and leisure, such that unemployment is no longer inversely tied to security or even comfort—an increasingly sharp requirement at this point in American history. This also implies that the cultural totalitarianism of political or economic models that are oriented towards a frequently illusory "proletariat" are going in the wrong direction: that, rather than making sure that everyone works all the time, we should be thinking of lives oriented towards projects, creativity, and social connection—in fact, that we should be creating a new universal aristocracy, rather than a universal peasantry.

[16] But these speculations from futurology and science fiction may be too vast for this discussion: from our more limited point of view, what is important is that we recognize that the flexibility of working hours and workloads in academic life is well worth preserving, for a variety of reasons. It seems obvious to me that thinking, understanding, and writing are, for

most people at least, of considerably poorer quality when one has to work long hours; and perhaps we can even claim that those who are less physically robust, or more withdrawn from some activities, are often the same people who have more time to think—and who thus may be the ones who contribute most significantly to the entire world of the intellect. This could be compared with the increasingly wide range of psychological studies (Young-Eisendrath 1996) of people who have lived with various problems or limitations, and how a certain percentage of them can be shown to actually have more to offer and engage more widely in helping others.

[17] And perhaps there is a need for us as academics to have more care, and more regard, for those who may have physical or mental disabilities, not merely out of some form of empathy, but because, in many cases, they may carry forth the best of our work.

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