



## “But You Don’t Look Sick”: A Survey of Scholars with Chronic, Invisible Illnesses and their Advice on How to Live and Work in Academia

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### Introduction: Disability and Academia

[1] The logical consequence of Disability Studies is that its principles are used to gain full inclusion for disabled academics. Beyond a method of analysis and scholarly inquiry, Disability Studies helps to put those stigmatized as inadequate on a par with those who inhabit the able-bodied world. “Disability” is seen not an impairment, but as a social construct, created by a society that excludes those who do not conform to an imagined status quo. “A disability must be socially constructed; there must be an analysis of what it means to have or lack certain functions, appearance, and so on” (Davis 2002, 56). Disability is usually imposed from without:

Disability [is] a disruption in the sensory field of the observer....[It] is located in the observer, not the observed, and is therefore more about the viewer than about the person using a cane or a wheelchair. The term *disability* is a categorization tied to the development of discourses that aim to cure, remediate, or catalog variations in bodies. Thus, disability is part of a continuum that includes differences in gender, as well as bodily features indicative of race, sexual preference, and even of class.<sup>(1)</sup>

The term disability is both helpful and harmful to those who could fall under its umbrella. The category engenders images of helpless, hopeless individuals who are without purpose or meaning in society, who cannot contribute towards society, and who must rely upon others for assistance even with the simplest tasks. However, these associations are merely products of society, and do not speak of the experiences of those who fall under the umbrella term of “disability.” The disabled are merely individuals with unique challenges in life, who require creative solutions to these challenges. When given the necessary accommodations for such creative solutions, most disabled persons are able to complete required tasks. The term disabled is only beneficial for acquiring needed accommodations; afterwards, it becomes harmful and marginalizing.

[2] Academia is both accommodating and exclusionary of disabled scholars. The flexibility of academic research can be very manageable, for example, but the grueling demands of teaching and research can be challenging for those with chronic illnesses. Many persons with auto-immune diseases and mental illnesses experience frustration gaining acceptance and support from their peers and colleagues. The disabilities and symptoms they experience are concealed, yet can be unpredictably debilitating. There seems to be no universal precedent for fairly accommodating scholars with such chronic,

unseen illnesses; many sufferers worry about stigmatization, and do not want their acute mental faculties or scholarly aptitude to be overshadowed by their disabilities. Furthermore, many of these illnesses require creative accommodations that are unprecedented in many departments and universities.

[3] I have undertaken a study of the challenges faced by scholars with invisible auto-immune diseases and mental illnesses—this paper represents a preliminary survey of my findings. I have compiled a list of strategies and accommodations employed by scholars in the UK, USA, Australia, and continental Europe. In presenting that information here, I hope to illuminate the ways that scholars from around the world might learn from each other to deepen mutual understanding of the accommodations required by differently-abled scholars. I will show that, with appropriate accommodation, scholars with disabilities can be successful in their careers and an asset to their musical disciplines.

### **The Surveys**

[4] As part of this study, I have conducted surveys and interviews with scholars who face unseen physical, mental, and emotional obstacles. Interview and survey topics focused on the ways in which illnesses have affected a respondent's academic career, what accommodations have been sought, the extent to which the respondent's home institutions acted in accordance with the [Americans with Disabilities Act](#) or other national law (for scholars from Great Britain, Europe, and Australia), how the respondent discovered the agencies or offices at her university that assist disabled persons (if such an office exists), and how colleagues and/or instructors have responded to the knowledge of their disability or the accommodations enforced as a result of it. There were fifty scholars who responded to my advertisements on the e-mail discussion lists of the Society for Music Theory, the American Musicological Society, the Disability Interest Group of the Society for Music Theory, the Royal Musical Association, and on web logs maintained to promote interaction and support for disabled scholars and artists. Thirty-nine scholars returned the surveys, and twenty-five of these agreed to phone, e-mail, or personal interviews. The majority of survey respondents were female: only six of the respondents were male. The nationalities can be broken down as follows: American (26), Australian (2), Canadian (2), continental Europe (5), Irish (1), and United Kingdom (3).<sup>(2)</sup> The respondents' rank in academia varied greatly, although all but five were or had been active in the fields of music academia: three master's students, seven doctoral students who were still in coursework or had not yet achieved advanced standing, eleven doctoral students who had achieved ABD status, six non-tenured professors, and twelve full professors who have achieved tenure. Twenty-five scholars agreed to phone interviews of 60-90 minutes, but because of privacy concerns, only five agreed to multiple interviews or extensive e-mail correspondence. In the phone interviews, I asked the respondents more detailed questions about the information given in the survey, and asked them to expand upon their experiences as disabled scholars and whether or not they would be willing to make their illnesses public. After allowing time for the respondent to add comments or anecdotes to their survey responses, I asked the participants to describe how they would re-invent academia in order to be more inclusive of disabilities, to give their feelings on being public about their invisible illnesses, and to discuss how the invisible nature of their illnesses complicated or simplified their quests for accommodations. Those who had two or three phone interviews shared extensive material about their experiences and the discrimination or accommodation they faced, or explained why they chose not to seek accommodations of any kind. Anonymity was very important to the respondents, and therefore the surveys and interviews will be available on an as-needed basis and only if respondents have granted permission. Of the twenty-five scholars interviewed, twenty did not want to be public about their ailments, while five were willing to be open and "come out" as scholars with invisible illnesses. Of these "open" scholars, two are no longer pursuing doctoral degrees in music and have given up academic careers, two are tenured professors who claim not to have experienced discrimination, and one is a graduate student who also claims to have avoided discrimination. Those who do not wish to become public about their illnesses resist because honesty in the past made their careers difficult, or because they were told by other academics with invisible illnesses that they would destroy their careers if they were honest.

### **The Results**

[5] The ultimate goal of this project is to provide musicologists, music theorists, and composers with an educational resource both for musical scholars with disabilities and for an entire music-scholarly community that seeks to work effectively with colleagues and students who have invisible, chronic auto-immune diseases and mental illnesses. It is my hope that future scholars with chronic illnesses will not face the same discrimination that others and I have faced and that future academicians will be more successful in their endeavors because of this study.

[6] As I describe the results of my study, I will refer to the faculty and graduate students alike as "disabled scholars," "differently-abled scholars," "chronically ill scholars," or "scholars with invisible illnesses." When it is necessary to

differentiate between faculty and graduate students, I will do so, but it is cumbersome to make the distinction at every turn. Invisible illnesses are defined as chronic illnesses that negatively affect one's health either moderately or severely, but are not readily visible. I have categorized the invisible illnesses into four groups. It is possible that scholars will have illnesses from multiple groups, as there is a connection between auto-immune disease and mental illness, especially depression. Similarly, to have more than one auto-immune disease or mental illness is fairly common. The largest collection of these diseases is the group of auto-immune diseases produced by an overactive immune system. In individuals with auto-immune diseases (many patients have more than one), the immune system is overzealous and attacks healthy bones, organs, tissue, skin, or other bodily functions and systems. Examples include rheumatoid arthritis, systemic lupus erythematosus, Crohn's disease, Addison's disease, celiac disease, chronic obstructive pulmonary disease, type I diabetes, and Graves' disease.

[7] Another group of invisible illnesses are the mental illnesses, such as bipolar disorder, schizophrenia (which may be linked to auto-immune disease), major depressive disorder, anxiety and panic disorder, borderline personality disorder, obsessive-compulsive disorder, anorexia and bulimia disorder, autism spectrum disorder, epilepsy, and attention deficit hyperactivity disorder. In mental illness, the terms used to describe the experiences of those who have been diagnosed are problematic, since many would argue that autism or ADHD are not disorders, but merely cognitive differences and alternative modes of life experience.

[8] A third large group of invisible illnesses are respiratory illnesses, which can overlap with auto-immune diseases. These illnesses can be caused by outside sources, and are not always inherent in a person's genetic material. Examples of such illnesses include asthma, sarcoidosis, idiopathic pulmonary fibrosis, acute respiratory distress syndrome, hypersensitivity pneumonitis, and chronic, severe respiratory allergies to airborne chemicals.

[9] The fourth group of invisible illnesses consists of medical syndromes that are not generally recognized to be auto-immune diseases, or to have any identifiable medical cause, but that operate in a similar way, cause symptoms similar to auto-immune diseases, and can negatively alter and affect lives. Some medical professionals do not recognize these illnesses as bodily diseases, but attribute their existence to a psychological problem. The syndromes that involve a bodily ailment that professionals can verify have been fully legitimized. For the sufferers of the "illegitimate" illnesses, however, the pain and discomfort faced is very real. Examples include fibromyalgia, endometriosis, poly-cystic ovarian syndrome, irritable bowel syndrome, chronic fatigue syndrome, vulvodynia, and Morgellens syndrome.

[10] The common complaints of the twenty-five scholars who responded to the survey, and which were echoed by participants in phone interviews or e-mail correspondence, include the following:

- *Difficulty in finding out about institutional resources.* Respondents generally received no assistance in finding disability services offices, or were unaware that an office existed to facilitate accommodation requests.
- *Unhelpful disabilities offices.* Respondents generally found the disabilities offices at their home institutions to be unhelpful. Usually, such offices advocate more for the university than for the scholars, especially in the case of graduate students and faculty, although services to undergraduates are sometimes useful. Accommodations that are difficult for the university or departments to enact are seen as a last resort, even if the easier-to-grant accommodations are not as useful for the disabled scholar. Disabilities offices in the US often fail to educate scholars regarding their rights under the Americans with Disabilities Act.
- *Uncooperative colleagues.* Respondents report that their colleagues are often uncooperative in facilitating accommodations from the onset of the illness or from the time the illness was made public. Accommodations were often delayed, if given at all.
- *Inappropriate invocations of "fairness."* Scholars with invisible illnesses often hear complaints about it being unfair that the disabled scholar should be allowed accommodation since "healthy" academics are not given the same assistance; consequently, many scholars are shunned by "healthy colleagues" who are jealous of the accommodations given to the chronically-ill scholars.
- *Refusal to offer accommodation.* Respondents report resistance or even outright refusal to provide necessary accommodation, especially in adapting degree or tenure requirements. For example, some scholars who were unable to complete courses due to debilitating illness or physical inability (such as with rheumatoid arthritis, which impairs fine

motor activities) were not accommodated beyond allowing for extra time. Having more time to complete an assignment is unhelpful if one is not able actually to write, and software programs like *Dragon Naturally Speaking* are virtually impossible to use with foreign languages and music notation, without numerous inaccuracies that must be corrected by hand. Scholars who requested extra time to satisfy tenure requirements, due to recent surgery or a flare-up in illness, had their requests denied.

- *Lack of flexibility with deadlines.* Respondents, especially graduate students, report that their supervisors often refuse to be flexible with deadlines to decrease stressful situations that exacerbate illness. Or, when accommodations are made and flexible deadlines are assigned, the differently-abled scholar is treated poorly and is resented because of the accommodations, especially if the assignments are not completed within a timeline the supervisor (who often has no experience with the demands of invisible illness) thinks reasonable.
- *Lack of funding.* Advanced graduate students with invisible illnesses worry they will be denied funding to support their efforts due to their chronic sicknesses. Three graduate students who responded to the survey did not receive funding by their departments, who chose to give the money to “healthy” scholars instead. Since there was no funding available, these three scholars had to work several jobs while in school to support themselves and their families and pay for tuition. While it is true that there could be myriad reasons for denying funds to a scholar with invisible illness, two respondents had plausible reasons for reaching the conclusion that their illnesses were to blame: one respondent heard from a third party that funding was denied because the scholar might not be healthy enough to complete the degree, and another was told point blank by the adviser that funding was unlikely because of the scholar’s constant requests for extension of deadlines, which were due to illness. All three scholars suspected that the large workload on top of full-time study exacerbated their illnesses and made them further disappoint their supervisors when they asked for additional accommodations. Some graduate students experience difficulty obtaining funding if they want to study part-time in order to accommodate the often invasive treatment for their disabilities. Most institutions do not give funding to part-time students, who are therefore forced to work while completing their degrees. This complicates the situation of disabled scholars immensely; it is even more difficult for a chronically-ill person to work while attending to full-time coursework and a grueling treatment schedule.
- *Confusion of physical and mental disability.* Colleagues and advisors conflate physical inability with assumed mental inability or a lack of intellect. Quotations of colleagues and instructors from some scholars’ experiences: “You cannot be a scholar because you are too sick; [sic] it is not that you are sick that prevents you from succeeding, but that you are not clever enough.” “You will never be upbeat enough with undergraduates because you are so depressed about your illnesses, therefore I cannot support your completion of the PhD, nor can I write you any recommendations, because I don’t think you can eventually perform sufficiently as a scholar.” Conversely, disabled scholars argue that their perceived mental shortcomings could be due to a wide variety of outside influences, such as medication side effects, severe fatigue, and severe pain. Scholars who are accommodated do not hear the same complaints about their mental prowess, or lack thereof, as disabled scholars who are refused accommodations.
- *Pressure to compensate by over-achieving.* Disabled scholars feel they must work even harder than “healthy” scholars to overcome their illnesses and gain acceptance, even though such high levels of stress and activity further exacerbate their illnesses and make it more difficult to complete their degree program, achieve tenure, or produce a sufficient amount of work. Disabled scholars feel they must be above reproach, since many colleagues view them as “sick” members of the department and overly scrutinize their productivity rate. Any shortcoming is blamed on the illness and used as evidence to prevent graduation or tenure. Disabled scholars constantly have to prove that they deserve to earn their degree, or tenure, or respect as experts in their field. Common complaints include being told they cannot study or complete their degrees and that they must find a different career, as if there would be no discrimination in other fields. The respondents feel that because they often work harder than others in their departments, and are often the most fastidious and dedicated, they should be accommodated and not discriminated against. Furthermore, the twenty-five respondents who were interviewed stated that because of their disability and the high levels of time management required to juggle a chronic illness and academic work, they were more productive and successful than their able-bodied peers.
- *Risks and costs of concealment.* Some disabled scholars state a strong desire to be judged on their intellectual abilities alone, not their illnesses, so they prefer to keep them secret rather than risk exposure and discrimination, even at great risk to

their health. In several instances, scholars have endured surgical procedures and have sustained serious health risks because of demands made by their supervisors or colleagues. The scholars were so petrified of having to divulge the chronic, persistent nature of their illnesses and felt so stigmatized by their colleagues, that they would rather endanger their health than be honest about needs for accommodations. While the lack of honesty meant that they were no longer discriminated against, in some cases it prevented them from success in their field: Several scholars interviewed were forced to take medical leaves of absence because their health was so worn down from the demanding work schedule. In the end, successfully obtaining accommodations was less time-consuming and more beneficial for the scholar and the administration.

- *Pressure toward undesirable disclosure (privacy concerns).* Some of my respondents report that they have been pressured to disclose the full extent of their chronic illnesses in order to receive appropriate accommodation. This pressure toward disclosure flies in the face of legal privacy requirements, which mandate that only the existence of a legally protected disability, not its details, need be disclosed.
- *Special stigma of cognitive or mental disability.* Scholars with temporary impairment of cognitive functioning due to emergency situations (such as injuries from accidents) and those who experience mental “fog” and concentration problems due to multiple sclerosis, fibromyalgia, attention deficit disorder, and the like find that they suffer the consequences of having their intellectual abilities underestimated. Scholars with mental illnesses have been ostracized from their departments, since many scholars do not recognize mental illness as real and therefore will not grant accommodations or give these scholars any assistance or empathy.
- *Lack of empathy from colleagues.* Scholars and suffering from severe chronic fatigue because of fibromyalgia or chronic fatigue syndrome did not receive empathy for suffering from chronic fatigue, because “we’re all very tired!” Similarly, scholars with chronic allergies and asthma are branded troublemakers, since “we all have allergies” and no one else asks for accommodations. One scholar whose chronic illness occurred because of an accident experienced discrimination after the symptoms became chronic and it was obvious they were not disappearing with time. The supervisor claimed that he was faking his injuries so that his workload would be lessened: The scholar was branded as “lazy,” and his accommodation requests were not granted.
- *Requirements for documentation and medical proof.* According to my respondents, scholars find it difficult to receive accommodations until their chronic illnesses have been given a “real” medical basis and have been legitimized by a physician. This is unfortunate for those with illnesses that often take a long time to diagnose, such as multiple sclerosis, or for those with illnesses that are not yet recognized by a governmental agency such as the Center for Disease Control. One respondent experienced symptoms that affected his work as a graduate student for over a decade, as it took that long for the medical establishment to discover he had multiple sclerosis. During that time, he asked for accommodations, but was sometimes unsuccessful due to the fact that he could not produce a doctor’s note outlining his diagnosed medical condition. This student has not yet finished a PhD degree.
- *Misplaced privacy concerns.* My respondents report that, out of concern for patient privacy, many university administrations are now forbidding health care centers to write notes of assistance for students who use their services. Students whose health insurance forces them to use university-sanctioned health-care providers cannot obtain letters of explanation about the seriousness of their chronic illness, and therefore these students are unable to receive accommodations from university faculty or employers.
- *Difficulty in obtaining relatively demanding accommodations.* Respondents to my survey report that faculty members and graduate students occasionally receive unofficial accommodations for a disability, but that such accommodations are more likely when they are relatively easy to offer (such as when graduate students require extensions of deadlines for research papers), and rarer for more demanding requests (such as changing the format of an assignment or an exam, for example, by making an assignment or an exam oral instead of written). Faculty seeking tenure and graduate students planning to enter the job market were the least likely to seek and receive accommodations or to make their illnesses public.

[11] Accommodations sought by respondents to my survey include the following:

- *Flexibility in scheduling.* A large number of respondents have sought the power to adjust their teaching schedule to

ensure that they teach when they are most likely to be healthy. For example, professors suffering from migraines sometimes request not to be required to attend meetings or teach classes in the morning, while those with fibromyalgia may request exemptions from evening seminars, lectures, and recitals.

- *Deadline extensions.* Many of the respondents have asked for deadline extensions for seminar papers or for producing work necessary for tenure.
- *Changes in format, length, or scheduling of exams and assignments.* Student respondents have requested accommodations for examinations, such as typing up responses on a computer rather than writing for scholars suffering from rheumatoid arthritis or multiple sclerosis, or postponing exams until a later date to accommodate chronic illness or necessary surgical procedures.
- *Adjustments in course load.* Many respondents to my survey have made requests for reduced course load or lighter teaching schedule due to severe, debilitating chronic illness. Scholars with severe chronic fatigue as a result of their illnesses request teaching or coursework schedules that meet in the afternoons, rather than forcing themselves to awaken very early or to stay awake late at night. Similarly, music performers with chronic fatigue request a decrease in the number of required performance ensembles, since their illnesses prevent them from learning so much music or attending so many rehearsals.
- *Online or distance teaching.* Many scholars with chronic illnesses have become technologically adept, and have requested as many online distance courses as possible, rather than reducing their teaching or coursework loads.
- *Office relocation.* Several of the scholars in my survey have asked that their offices be moved to chemical-free zones or, at the very least, away from mildew-infested buildings that exacerbate severe allergies and asthma. In addition, some have requested offices closer to parking, since extensive walking exacerbates pain symptoms.

[12] In a number of situations, respondents either did not seek or were denied accommodation of any kind.

- *Mental illness.* There is little or no precedent for accommodating scholars' mental illnesses, such as clinical depression or bipolar disorder. Scholars with mental illnesses (such as anxiety disorders, panic disorders, eating disorders, borderline personality disorder, bipolar disorder, obsessive-compulsive disorder, and major depressive disorders) often were unable to receive accommodations from instructors and colleagues personally, or even assistance from university disability services offices. There seems to be no precedent for accommodating the debilitating effects of mental illnesses. Even mental health professionals interviewed were unsure how to accommodate scholars with mental illnesses.
- *Gender-specific invisible illnesses.* Scholars with invisible diseases that are specific to one gender, such as endometriosis (bleeding of the endometrial lining in the uterus), polycystic ovarian syndrome (multiple painful cysts in the ovaries), or vulvar vestibulitis (severe inflammation and irritation of the vulva) were unsuccessful in their quest for accommodations. This lack of success was due, in part, to the uncomfortable nature of discussing reproductive or sex-related conditions with anyone other than a medical professional, and also in part to the negative treatment some women experienced from those of their own sex if they appeared "weak."
- *Younger scholars.* Young, usually junior, faculty members and graduate students with chronic invisible illnesses often did not receive empathy or accommodation because it was difficult for others to believe that debilitating chronic pain and fatigue could be compatible with youth.
- *Accommodations of long duration.* Scholars who requested accommodations over a long period of time were often met with more discrimination than those who requested accommodation for short periods. Indeed, scholars who continued to request numerous accommodations eventually had these requests denied. Universities and faculty were much more willing to accommodate invisible illnesses if they were perceived as temporary. Scholars who treat their problems as acute afflictions and do not disclose the real, underlying cause as a long-term disability are more successful in acquiring accommodations. Scholars who go through the long process of using the Disability Services offices or formally requesting assistance from the department chair achieve accommodations for a time, but in the end receive more discrimination than help.

- *Geographical variation.* Respondents from the UK generally fare better than their counterparts in the US. They appear to have relatively few problems receiving requested accommodations, such as flexible deadlines, extensions for exams and for dissertation/thesis completion, and even receive computers with valuable adaptive applications and software installed. One junior faculty member who has difficulty typing received a software program that enables her to speak the words into the computer rather than type, as well as a tutorial from a professional familiar with the problem, and a graduate student assistant to help with completing tasks, all at no cost to her. Conversely, respondents from the Continent receive virtually no accommodations.

[13] Many scholars with invisible illnesses feel that if they were granted accommodations and able to complete their work in a less stressful environment, their illnesses would be less severe and they would have finished their degrees or received tenure or pressed on in their work with less difficulty and more success. There were respondents with mental illnesses who experienced mental breakdowns and were forced to leave their jobs or drop out of doctoral programs because of difficult and disrespectful colleagues or professors. One graduate student respondent writes that upon asking for accommodations, the graduate student was accused of lying about or misrepresenting the seriousness of the disability; instructors demanded to know the full extent of the disabilities and claimed to be more qualified than medical professionals to choose appropriate accommodations. The majority of scholars interviewed wanted greater flexibility in scheduling and in completing course requirements. All of the respondents wrote that dealing with the treatment of their invisible illnesses and the symptoms caused by their illnesses slowed down their productivity rate. Many requested extensions on finishing coursework, or their dissertations, or on the tenure process, or they took a medical leave of absence. Many scholars also write that after living with illnesses as academics over the course of several years, they developed techniques to overcome their disabilities and their productivity rate increased immensely. Several respondents wrote that they are now the most productive members of their department, because they have been forced to evolve as scholars and to overcome their differences.

### **Concluding Remarks**

[14] For the scholars with disabilities whom I surveyed, their experiences and outcomes vary considerably. Not surprisingly, scholars further along in their careers, with full-time positions and, possibly, tenure, find it easier to deal with their disabilities, at least in part because they have a significant degree of control over teaching schedules and professional deadlines. As for the extent to which scholars are open about the nature of their disabilities, there is no absolute correlation with good experiences or outcomes. Many full-time scholars—even those who are tenured—are afraid to be open about their illnesses and therefore are reluctant to assist the students who come to them requesting accommodations. These scholars want to share their experiences and, in confidence, counsel the student, but fear that becoming activists against disability discrimination will make them unpopular in their departments and might cost them position or promotion. People with illnesses, especially invisible illnesses, face numerous dilemmas when requesting accommodations. They may try to “get by” with minimal accommodations and appear strong despite the illness, but this approach prevents them from getting the assistance and accommodations they may need to complete degree or tenure requirements. Or they may emphasize the need for accommodations and assistance, to the detriment of scholarly reputation. The second approach frequently leads to diminished accommodation over time as the scholar is marginalized. Openness, then, would seem to cut in two opposing directions: beneficial for some, destructive for others.

[15] Administrators and academic staff can be determining factors in deciding whether a scholar with invisible illness will have an easy or difficult time obtaining accommodations. The role of the offices of disability services is to act as an unbiased intermediary between department and scholar, with a goal of collecting data about a scholar’s illness and communicating the information to the department in such a way that a scholar can obtain accommodations without revealing too much information about their conditions. If a scholar does not wish to divulge every detail of his or her illness, then the office of disability services can have a medical doctor evaluate the scholar’s conditions and claims and then send an official letter of accommodations approved by the office medical personnel. The university and department are required to abide by these approved accommodations. Major research universities implement this third-party system to ensure that they are abiding by the Americans with Disabilities Act, although there are still many smaller liberal arts colleges who do not have disability services offices. When institutions lack offices devoted to the needs of the disabled, scholars must plead their case directly to faculty and staff. The respondents interviewed had both good and bad experiences with disability offices, although some complained of not receiving approval for much needed accommodations and preferred to seek accommodation from professors and staff directly. A faculty member, an administrator, and a disability services liaison were interviewed for this study, and all three were happy to provide necessary accommodations for scholars with invisible illnesses. The focus of the

survey to the faculty member was the issues of workload limitations, tenure, and funding decisions. The faculty member reiterated the sentiments of the professors with invisible illnesses who answered my survey: most fellow faculty with invisible illnesses overcompensated by teaching and publishing more than their non-afflicted colleagues. The faculty member had no problem with scholars with invisible illnesses postponing tenure due to sickness, as long as such illnesses were documented and the scholar had some type of plan in action for completing work when health returned. The administrator interviewed was even more lenient, and felt that graduate school is such a difficult enterprise that students without health concerns should be given leeway in completing work and postponing exams. The disability services liaison insisted that faculty are not usually mean-spirited in their reluctance to honor accommodation requests, but are genuinely concerned with ensuring that all students are treated fairly and equally. Therefore, it is not unreasonable for faculty to insist upon documentation about a student's legitimate right to special accommodation before granting their requests.

[16] The high-pressure atmosphere of academia causes particular difficulties for scholars with disabilities. Scholars in full-time academic posts often experience discrimination at the hands of colleagues who believe they are not "pulling their weight" in the department due to missed meetings or inability to do more administrative work under the effects of their illnesses. Scholars brag that they get by on little sleep; like a rite of passage, "We all get tired" is the oft-repeated slogan. Scholars pride themselves on keeping full schedules that leave little time for sleep or relaxation: vacations are discouraged and are really just excuses for more reading and work. One professor with an invisible illness was told to keep her conditions a secret as long as possible, as her colleagues would turn on her the moment they could "smell blood" and claim she could not "make it later on" because of her chronic illnesses. The environment is fiercely competitive and the high standards that exclude anyone who requests more flexibility or accommodations for illnesses are impossible to meet.

[17] Every disability poses challenges to a career in academia. It is clear from the testimony of my respondents, however, that invisible illnesses pose serious challenges, and that short-term or improving illnesses are more likely to be successfully accommodated than long-term or deteriorating ones. The challenge of obtaining accommodations can be more difficult for scholars with invisible illnesses, since these scholars must go to the trouble of arguing for accommodation and supporting their requests with extensive documentation. Conversely, scholars with visible disabilities, such as blindness or a broken arm, have obvious evidence to support their claims and normally do not need to argue for accommodations. It is also clear that scholars with disabilities fare best when they have faculty and colleagues who are sympathetic and have previous experience working with disabled scholars, and when their university's administration (dean, ombudsperson, judicial board, etc.) have previous experience with disabled scholars and are proactive in fighting for accommodations. The experiences of the respondents vary widely depending on the empathy, understanding, and education of the university administration and the departments. Graduate students and junior faculty who happen to attend empathetic institutions have appropriate accommodations provided without question, and are given equipment to assist productivity, such as computer equipment, graduate student or undergraduate student assistants, a stipend to purchase an outside assistant, or are loaned equipment from the Office of Disability Services. While most universities have disability services offices, many of these offices are not as helpful for graduate students and faculty members. In instances when a disability office "certifies" an illness and outlines necessary accommodations, many times the granted accommodations are not sufficient for the student or faculty member and serve the best interests of the department and administration rather than the disabled person. Several respondents continue to lobby for accommodations they desperately need, that their disability office will not certify, and therefore their departments will not grant.

[18] The alternative to enforcing policies and legislation that ensure the full inclusion of disabled scholars is to ignore the discrimination and to ignore the value of the contributions of disabled scholars and disability studies. Academics are badly educated about the rights of disabled scholars, and are naïve about the discrimination that disabled academics experience. To allow discrimination against disabled academics to continue is to ignore the ideas and contributions they could bring to the scholarly community.

[19] Very few of the scholars interviewed had positive experiences with their university after "coming out" as living with chronic illnesses. The relatively small number who felt they had been treated fairly and had been appropriately accommodated were generally those fortunate enough to have had colleagues with prior experience in accommodating disability and with knowledge of disability law. Faced with the risk of negative and damaging consequences, most respondents remain unwilling to be open about their disabilities. Respondents who are unwilling to reveal their disabilities report that their concealment creates its own painful emotional and physical damage: scholars who choose to keep their chronic illnesses a secret and push themselves to operate on the timeframe of "healthy scholars" live in constant fear of being found out, or of being unable to meet the demands of academic life. Those who have come out, despite experiencing

different degrees of discrimination, are generally happier to have the psychological weight of pretending and hiding lifted—they feel relatively free from requirements that are impossible to fulfill or dangerous to their health.

[20] Although my view is not universally shared among the respondents to my survey, it is my own strong conviction that it is usually better to be open rather than closeted about disability or illness. As scholars with disabilities, we need to be our own vigorous advocates. The accommodations we need and deserve—not as a matter of pity or even empathy, but of simple justice—will not come to us unless we seek them. And we need to encourage a corresponding openness to communication about illness and accommodation among our colleagues and professors. Scholars without disabilities must learn to consider the whole personhood of disabled scholars. Scholars with invisible illnesses can never hope to achieve full inclusion unless academia as a whole becomes more open to granting full and generous accommodations. What is truly necessary is a radical change in how disabilities are perceived by the scholarly community: differences, not deficits, as the familiar slogan within Disability Studies has it. Beyond fostering a healthy environment for disabled scholars, establishing an academic working environment that is accepting of difference and more malleable to the needs of each individual scholar would be beneficial for all scholars. As numerous medical reports attest, high levels of stress and competitiveness not only wreak havoc on the immune systems and general health of disabled scholars, but are also catalysts for serious health conditions in otherwise healthy individuals. Scientific studies have shown that loss of sleep and high stress levels weaken immune systems, and have been linked to aggravating the symptoms of cancer and increasing the chances of developing virus-related cancer.<sup>(3)</sup> I contend that if academia is allowed to reinvent its view of disability and to be proactive in accommodating scholars with disabilities, the academic environment will be healthier and more productive for all concerned—disabled or not.

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## Footnotes

1. [Davis 2002](#), 56. To Davis’s “person using a cane or a wheelchair,” I would like to add the person with an invisible illness who has come out publicly.  
[Return to text](#)
  2. The exact countries of participants from the European continent or the United Kingdom are unspecified to protect the privacy of these individuals in music academia.  
[Return to text](#)
  3. See [Reiche, Nunes, and Morimoto 2006](#) and [Segerstrom and Miller 2004](#).  
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