



Scholarship and Quadriplegia

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[1] Disability can make scholarship a challenging enterprise. I have faced such challenges for over 20 years now, so my experiences both as a quadriplegic and paraplegic may prove useful to others in comparable circumstances. It is in this spirit that I offer the following comments.

[2] I was diagnosed with multiple sclerosis in 1988, a year after being appointed at Lawrence University as an Assistant Professor of composition, theory and music history. My condition was more or less invisible for a couple of years, but in 1990, after winning the school's teaching award, my legs began to fail and I started to use a cane. Soon I graduated to a scooter and modified Dodge Caravan in order to get around. I maintained my position (and received tenure) as a paraplegic until 1996, when I began to lose the use of my arms. I became fully quadriplegic a year later, and retired from my position in 1998.

[3] Since then, I have done all I can to maintain a presence in the field. I have published articles in academic journals, contributed book, CD and DVD reviews to a well-known classical record magazine, broadcast a monthly radio show on a local NPR affiliate, lectured at various institutions, and even taught as an adjunct professor at a nearby college. In short, I have tried to do everything I used to do—given my limitations and changed circumstances. It is those limitations, some intractable, some imposed, that I intend to address.

[4] Every disability is different and presents different obstacles; thus I can only speak of my own individual experiences, freely admitting their likely inapplicability to other situations involving physical compromises. I would like to concentrate on issues specifically involving musical scholarship, that is, research, study, and generation of legible and submittable scholarly work in the field of music, produced without the use of one's limbs. Music scholarship entails special demands for a quadriplegic scholar, including the task of score reading, the necessity for page turning by skilled assistants, generation of complex examples in (often modified) musical notation with programs usually incompatible with existing voice activation software, copying of musical examples, and so forth. Not being a computer scientist and lacking consistent technical support are obvious problems, as well as the quite catastrophic evaporation of library privileges following resignation from a teaching position. It is hard to overestimate the consequences such a loss entails for the sustenance of serious scholarship. I will return to this issue below, but for now simply cataloging related problems as they come up in my daily routine of reviewing and writing might be of value.

[5] I have currently been studying the work of Swedish composer Allan Pettersson, who himself fought physical disability for most of his career, and have been evaluating the literature surrounding his music from the perspective of current work in Disability Studies. First, a word on how I wrote what you are reading. I use a voice activated program called DragonDictate

which enables me to dictate text into my computer. This is, of course, a miraculous development, but still nothing in quadriplegic disability is possible without the assistance of people with the use of their hands.

[6] My day begins with my aide turning the computer on and fitting me with a headset. He must click on the DragonDictate icon manually to start the program for me. This obviously cannot be done without assistance. Once in, I am able to compose text and use the Internet. If I need to work with printed text, I must have the aide turn on my printer manually and retrieve the printed document or documents. These must be manually laid out in such a way that they can be read by me. Page turning and text distribution or ordering is another task that requires assistance.

[7] Part of my research involves analysis of two works by Pettersson, his Sixth Symphony and Second Violin Concerto. First, the listening to these pieces requires an assistant to take the CDs out of their jewel boxes and place them in a CD player. The aide then needs to press “play” or “pause” (or “stop”) when required. In terms of the standard music-scholar activity of following a score, there are a number of obstacles involved for the quadriplegic scholar. First and foremost is the very procurement of the score itself. Since severe disability usually requires retirement from a university position, use of the kind of library required for such an activity as score study entails the generosity and cooperation of often distant colleagues. Regarding the study of existing published scholarship, the finding of a research librarian in such a situation requires luck. A number of important Internet resources, such as ProQuest and JSTOR, require subscription, normally through academic libraries. Access to standard reference materials such as Grove's is not automatically available online in all public library systems (underscoring the differences between public and research libraries). Foreign language materials require special academic resources. The scores themselves are more often than not prohibitively expensive, assuming they are actively in print (often a significant assumption nowadays). The difficulty working as a music scholar in a non-music reading society is magnified profoundly when one is dependent on public institutions. (This issue in itself requires serious consideration from the academic musical community in general.) Along similar lines, manuscript study and related activities often require travel and specialist involvement not usually available to scholars with physical compromises.

[8] Copyright laws often have the effect of interfering with the ability of the disabled to participate freely in the access of information. The Society for Music Theory is one organization that has made their publications available online, though only by fairly expensive subscription, which might be an issue for disabled scholars whose income is limited due to financial constraints imposed by their disabilities. Again, once institutional affiliation is lost, access to information becomes an issue—not all scholarly publications in music are available online, and neither are their back issues, unless one can access them institutionally. Regarding information access, it might be useful to consider Project Gutenberg, an excellent resource for quadriplegics dependent on literary material available online. Project Gutenberg, at this time, is limited to publishing literature online whose copyright has expired 70 years after the author's death, effectively making most 20th century literature unavailable to readers unable to turn their own pages. Recent literary works are in turn effectively unavailable to quadriplegic readers since most are unavailable in accessible form. A similar situation exists for scholarly publications in music, most of which are prohibitively expensive for purposes of perusal or research, or simply unavailable without privileged access. Recorded music is also difficult to access, online or otherwise, for scholarly purposes, particularly if the repertoire under study falls outside traditional genres.

[9] Of course, much is possible, and modern technology keeps more doors open to those with severe physical disabilities than ever before. In an ideal world, needs that are taken for granted by healthy individuals but unavailable to those affected by illness, accident, or misfortune may—we hope—someday be successfully and thoroughly addressed by enlightened institutions, generous friends and colleagues, and a sympathetic—and financially able—research community. The quadriplegic condition is admittedly extreme, but perhaps other disabled scholars may find some of these issues in some way consonant with their situation and ambitions.

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