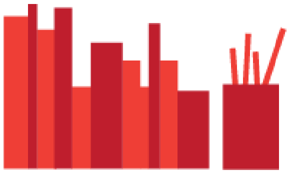
ADVOCACY AND INTERDISCIPLINARITY: Q&A WITH DR. GREGOR WOLBRING



ABSTRACT The Editorial Board of *JORI* had the pleasure of speaking with Dr. Gregor Wolbring, an Associate Professor at the University of Calgary, about his wide body of work as an ability governance researcher, a health researcher, a vari-ability/ability/disability studies scholar, a governance of science and technology researcher, a bioethicist, and a biochemist. The following content was produced in part by an in-person interview during his recent visit to NC State University and email correspondence.

JORI: Why did you want to be a biochemist?

Wolbring: Like many kids, I was thinking about being a physician. However I felt that this was unrealistic given that I am in a wheelchair. I assumed that patients would not accept a wheelchair-user as their physician. So I chose when I was 14 years old the next best thing in my mind, namely biochemistry because I could still do research related to human health.

J: What does being a researcher mean to you?

W: When I was making the decision to be a biochemist, it was about being a researcher in an academic setting. Maybe this was our generation. All the students that studied biochemistry with me had the goal of becoming a professor. As to research, I like to explore an idea, see where it leads me. And I felt that the university setting would allow me to do so. And it did. I was very fortunate that I could explore my ideas. My last 10 years before I took the faculty position in disability studies, I was paid by industry to work on thalidomide and its derivatives at my university whereby the project started with an idea that I pitched to the company. However I saw myself not only being a biochemistry scholar, but also as a person that looked at the social implications of science and technology in a scholarly way.

As such, I wrote for many years parallel to my biochemistry scholarly work on social implications of science and technology focusing often on the impact on people labeled as impaired. This might have been a logical add-on given that I am a thalidomider. But I also felt I can contribute something to the disability movement that not many had a way of doing, given my embeddedness in science and my access to academic literature. Therefore I wrote many academic pieces but also non-academic pieces such as my 70 columns on various aspects of nanotechnology. All my non-academic work is published open access and I try as much as possible to also publish my policy academic work open access because the community is as much my audience as are academics.

J: What do you think of open access?

W: I already alluded to the importance of open access. Again to just look at my community rehabilitation and disability studies related job in the moment. What I research, what I do, I do because I think it could benefit the disability community.

In this way I hope to contribute in a small way to the ability of the community to increase its competency on the issues I cover. As such I need to be able to publish open access so they can benefit from it. I do not do my work only for the few fellow academics that might be interested in my topics. Given that I am in the wheelchair, I also find open access important for visibility, as traveling is rather laborious and conferences are not very efficient, given the reality of the inaccessible world we live in. As cool as it was to be at NC State and meeting you guys, it worked with the NC State meeting as everything was taken care of. But for big conferences, no one does that for me. So open access increases visibility as does presenting by Skype/podcast/videocast.

As to my students, given that most of them want to work in the community after they graduate, open access is also important so the community can see what they do. And in case that the student engages with community collaborations, open access is even more relevant because the community partner should be able to send the data around they helped to generate. In the case that the community was triggering the project the student collaborated in, open access is even more essential. However, we are far away from a perfect open access world. Furthermore there seems to be in many circles the notion that publication of data in restricted-access journals is seen as “academic work” and data that is published open-access is seen as “non-academic work.” This sentiment is wrong and has to change.

Open access also allows my students to be visible globally and to build global networks that includes fellow students in countries that might not have access to the academic, non-open access journals, and faculty globally and NGO’s, Right? It also allows to link to communities globally. If you want to work with a NGO on water, they’ll only take you if you’ve worked on water. And if they find your publications online and the publication makes sense to them and they contact you, you are in a good position.

It’s all about visibility. That is also true for presentations. My students do many virtual presentations at meetings so we do not have travel costs and we put the talks online so people can find them.

J: Is policy work something you enjoy or is it something you feel more is an obligation?

W: I am a disability rights activists working on disability related policy work my whole life. This was triggered by the social realities I experienced as a disabled person. I felt that if I do not like the reality I live in I have to get involved in pushing for changes. And I chose on purpose to do this not as my job but on the side with biochemistry, my chosen career. As such I think both joy and obligation might be the wrong words. I don’t think one does advocacy because one enjoys it. Lobbyists might like it because they want to make money. It can be fulfilling, sure, but joy I think is the wrong word. In my case I simply felt that this was the right thing to do. There was a problem and I had something to say. As such I covered many areas from transportation to education, however, when I started my biochemistry education I added a focus on how emerging sciences and technologies impact disabled people. Given my training, I felt it was easier for me to write on genetics and its impact on disabled people and science and technology than most disabled people due to my training. And I also focused on bioethics discourses from a disability rights angle since 1988 which seemed to make sense given my science and technology focus.

Now when I took the disability studies faculty position I continued on with covering science and technology and bioethics and added some areas I did before such as education and I added areas that seem to flow from my science and technology such as sport.

J: What are the most important aspect of your research?

W: To just focus on my disability research, there are various aspects.

The Issue of relevance

W: One is of course that I chose research projects that I feel are of relevance to the disability community. There are so many issues we need data on and there are not enough people generating the data. A lot of my research can be seen as a foresight endeavor where I try to generate data on an emerging problem/issue whereby what I publish can be accessed by the disability community and used when needed.

The Issue of consistency

W: Much of my work is guided by questioning "Animal Farm" philosophies which disadvantage disabled people. You know "Animal Farm" is about some are more equal than others and I think there are many instances where other social groups are seen as more equal than disabled people.

To give just the example of the discussion around sex selection prohibition (Listen to the interview with Dr. Wolbring done on April 15, 2016 with Jim Brown from CBC.) In short many arguments are put forward to justify the prohibition of sex selection on the embryo and fetus level. However if one wants to use ability deselection or impairment deselection on the embryo and fetus level that's fine. It's a typical "Animal Farm" philosophy. All the arguments used to justify sex selection prohibition could be used to justify prohibition of ability selection or non-impairment selection. But the arguments used to justify sex selection prohibition are said not to apply to pre-birth embryos and fetuses that are labeled as impaired because they have a disease or are not "normal." This demarcation line of course is totally arbitrary set by people who do not see themselves as "diseased."

I believe this type of "Animal Farm" philosophy does not hold in the end. Indeed this philosophy didn't work for the pigs in the long run in *Animal Farm*. And setting up arbitrary lines based on having the power without a logic to it also does not work in the long run. In this case everything hinges on what is seen as a disease, as something "not normal" or as an "aberration." With more and more ways to tinker with genetics, including genetic enhancement, we will see increasingly changes to what is seen as as desirable, ability-wise. What is labelled as a disease constantly changes. Being gay is still seen as a disease in 77 countries. Down the road, not being ability enhanced might be seen as undesirable. Using disease as a demarcation line given that it changes constantly is very problematic.

The laws by themselves don't do much, so I never put much emphasis on them. It's really about what is the social dynamic that allows this stuff to come to pass and benefits these things. I focus much more on this kind of work than just simply "yes" and "no."

The Issue of not being ghettoized

W: I coined the field of Ability Studies even before I obtained the faculty position in disability studies because I felt ghettoized working on disability issues. I think one cannot change the world if one is ghettoized. If others see that the problematic dynamic also impacts them, one has a chance for change. Many of the dynamics that lead to the disablement of people labelled as impaired are also applicable to people not labelled impaired.
Indeed, ability expectations drive the disablement of people labelled as impaired but ability expectations are also used to justify sexism, racism, ageism, etc. So I build a lot of literature over time around ableism, which is the cultural phenomenon that certain abilities are seen as essential by some. As I see it, this ableism can be used to disable or enable.

Ableism was coined by the disability rights community to illustrate the disablement one experiences if one does not fulfill a form of ableism that expects certain physical, mental and cognitive body abilities. As such, the research done in disability studies and the lived experience of disabled people is relevant to everyone because everyone can be labelled as impaired. Everyone can experience disablement based on ability expectations (see how the disablement inherent to sexism, racism and ageism is often justified by claiming that the targeted group misses essential abilities).

However, one can also use ableism to enable. One could say that one wants the ability to experience peace, or to live in an equitable society. So in the way I use ableism allows me to build a positive narrative around ability expectations.

The Issue of interdisciplinary, transdisciplinary research

W: We talk about ivory towers and performing “interdisciplinary, transdisciplinary research” but I think it is not enough to link up different disciplines. However beyond that I think it is not going far enough I think the concept of interdisciplinarity/transdisciplinarity is not implemented well in many places. Often the “inter” is very limited such as, “we use science, engineering, medicine, nursing, and economics and we are interdisciplinary.” Often sociology is not part of it, or disability studies. So what they think is an “interdisciplinary team” is not very diverse. If it’s diverse, it really depends on how open the group is. I think the reality is not measuring up to behind the rhetoric. The NC State group that invited me seems to be very diverse, and I for sure talked with people from many different backgrounds. However it’s hard work to internalize all these different views /approaches which in the end has to happen. One has to be able to be in the shoes of others and not all the time depend on that everyone is there.

The Issue of students

W: Finally for me the most important part of my research is my students.

I love to teach students to do research. I also could not do what I do without my students and their interest in the topics I cover. I have, at the moment, 16 different projects with 12 different students. There’s so many topics one can work on. In regards to disabled people, there’s definitely a lot of data missing in a lot of areas as is in the broader aspect of ability expectations. And as it’s increasingly all evidence-based; we need a lot of data. All kind of issues need to be provided with evidence that something is wrong.

However I see my group of students not just as individuals that do projects with me. I see my student group as an organic entity as a group of people who support each other work-wise and outside work. Indeed they gave themselves a name and a logo, and they become a cohesive unit with a Facebook page, and Twitter handle, and alumni of the group still being involved. My students come from various backgrounds degree wise and topics they want to cover and we strive for everyone learning from everyone.

Now, I focus in particular on undergraduates as early as first-year students right out of high school. I am in a program where most students that graduate with their Bachelors will end up working in the community with disabled people or disability organizations or on disability policy.

My hope is that students that work with me on research projects whereby the project is tailored to the interest of the student allows the student to learn to do research and think like a researcher. My hope is that the student becomes a community scholar, meaning that the student who obtains a job in the community after their Bachelor or after their Masters, for example, will be able to identify research needs and to do research as a community member as part of their job. Check out my students' webpage to see the work we do!