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On dialogue: disability studies and science & technology studies

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By Laura Mauldin

I am grateful to Somatosphere for inviting to me to write a post for the blog. I was asked to write about the relationship between disability studies and science and technology studies (STS). So in this blog post, I want to explore some particular ways of thinking about this relationship.

I have been writing for some time now about the use of cochlear implants (CIs) in infants identified as deaf. I am currently finishing a book manuscript based on my dissertation research, which was a multi-sited ethnographic project in a CI clinic and other places encountered in the lives of families where a child received a CI. Throughout that project, I was interested in understanding and gathering stories about CIs in particular, but on a more general level I was trying to get at how a dual process – the increased medicalization of everyday life and the proliferation of new technologies — changes how we understand, act upon, cope with, and expect others to cope with human bodies. Part of what I want to do here is simply talk about what STS and disability studies are and why the intersection of these two fields is a rich space for investigating this dual process and how it brings to light our assumptions about bodies – what they should do, be, look like, etc – in the first place.

Disability studies explores the radical possibilities for living well in non-normative bodies and pushing back against the very imperative that bodies should conform to normative ideas in the first place. It critiques cultural and structural systems that get in the way of living well with disability and wants to changes these systems that penalize having different bodies/minds. For example, living well could mean having access to transportation and education, being employed, being able to live in the community and place of their choice. These are all basic structural needs that a staggering number of people with disabilities lack, not due to their disability but due to such things as the way that these social systems are built and/or organized. A useful starting point for learning more about disability studies is the website for the Society for Disability Studies: www.disstudies.org.

I see profound connections between STS and disability studies and one

reason for this is that sometimes technologies are important in achieving the goals of living well in non-normative bodies. Through technologies, we often all get introduced to pretty radical new ways of living and navigating the world. But sometimes, technologies get in the way of the goals of making disabled people's lives better. For example, technologies are often held up as a 'fix' for bodies (the development of 'cures' for various conditions, genetic therapies and other reproductive technologies, cochlear implants, etc.) and this use of technology often depends on the idea that the body is the problem rather than society, which runs counter to foundational tenets of disability studies. This argument was made in Sumi Colligan's excellent essay (2004) where she criticized an ethos of technology and medicine that she called "the moral imperative to fix." She made clear a powerful triumvirate of thinking: There is a connection between the medical or scientific possibilities for intervening on bodies, the ensuing moral imperative we often feel to "fix" them, and the lack of accommodation for those with disabilities that are here now and systematically excluded and discriminated against. That is, we as a society get enamored with technologies that aim to fix bodies instead of doing the social justice work of changing attitudes and social structures that disenfranchise people with disabilities.

Meanwhile, the field of STS examines science and technology in the social context. We might study the 'front end' of scientific and technological developments by looking at how cultural, political and economic values all affect what kinds of research and development get done. We might study the 'back end' by looking at such things as how they are deployed, marketed, sold, and represented in culture. On the macro level, STS considers ethical implications, how technologies and society change together, and what new questions and problems arise because of scientific of technological developments. On the micro level, we might look at how they are utilized, experienced, adapted, or re-invented by the very people that use them.

So technologies, and especially the power of medicine and medical interventions, are talked about a lot in disability studies. But, it is not always in dialogue with the field of STS. And while disability studies is having critical conversations about technologies, STS doesn't often engage disability studies on this topic. Why is it that disabled bodies and disability studies are so often 'written out' of STS? Disability communities and scholars in disability studies offer pivotal points of knowledge for getting at some of these crucial questions in STS, questions like: What are the lived experiences of disability and/or augmented bodies? How do our social institutions and healthcare/sociotechnical systems organize and shape these experiences? Whose interests are served? There's also an affinity between the fields that is equally important to discuss: both disability studies and STS are sometimes perceived as being

anti-technology or anti-science, which they are not. What both fields share is a commitment to nuance, to critical thinking about the ways we use technologies and the ways we use scientific and/or medical knowledge. This is what draws them together so well.

Furthermore, why is it that disability studies isn't more acquainted with STS? There's been some hesitance in the past on engaging with science and medicine in disability studies and for justifiable reasons. Since disability has long been understood as only a medical problem, seen through the eyes of doctors and others as only sites to be fixed, it can be hard to open up that realm to critical analysis. And this framing of disability as only a medical problem is still rampant today, despite the many gains made by the disability rights movement. Thus, it makes sense that much of disability studies is focused on cultural production and representation, on emphasizing the vibrancy of disability communities. It is of central importance to the field of disability studies and those in various disability communities to offer a powerful counter discourse. But I think focusing more on science, technology and medicine could also be fertile ground. There is a false divide between medical spaces and cultural spaces. Medicine, our healthcare systems, the technologies we have available to us, all of these are socially made and offer fodder for a disability studies analysis. For example, we can examine how technologies are ethically, culturally, and structurally complex whilst also claiming that we need to beware of seductive fixes on the individual level. In her work on prenatal testing, sociologist Barbara Katz Rothman put it rather succinctly: using technologies like prenatal testing that result in women having to make decisions about disability aren't medical decisions, they're social decisions (1993). In that sense, breaking down the false divide between science/medicine and culture by taking a critical disability studies view provides a platform for us to think more thoroughly and more radically about the possibilities that technologies offer and the possibilities that they take away – much like the critical work done in STS.

None of this is to say that there isn't any dialogue between the two fields. There are scholars out there who do publish at this intersection and are trying to deepen the conversation between the two fields, without the influence of whom I would not be contemplating the things I do. But I want to ask more people in STS to broaden their scope. After all, people with disabilities are the largest minority in the US, our bodies are increasingly able to be augmented and intervened upon, and there are increasing pressures (especially in the realm of reproductive technologies) on all of us to ensure 'optimization.' At the same time, our demographics are also changing. By 2050, more than 88 million people in the US will be over the age of 65, which is more than double what it is now (Vincent and Velkoff 2010). There is much overlap in the goals of those working to make life better for people with disabilities now and anticipating the needs that will

accompany these demographic changes. I also want to ask more people in the field of disability studies to make the realms of the medical, the scientific and the prosthetic, areas that we take up in our scholarship. A disability studies analysis, like feminism and other radical sociological ways of thinking, is one of the tools we have to critique the moral imperatives we put on individuals to fix themselves rather than collectively accommodating one another in this neoliberal era.

So what questions can we ask at this intersection of STS and disability studies? When I teach my courses, I always ask students to think critically and creatively about the tensions between changing bodies to accommodate society at the price of changing society to accommodate bodies. Are people obligated to use science, medicine and technology to optimize and/or normalize their bodies? How do these imperatives work upon individuals, shape how we organize our healthcare system, impact the research, design, and marketing of technologies? These are but a tiny selection of the questions relevant to both fields. As I have outlined, we've already got some starting points; the strengths of each field compliments the gaps in the other. And in endeavoring to bridge fields, I am always reminded of feminist science studies scholar Donna Haraway, whose piece Situated Knowledges (1988) I go to the most often, to simply ask: Whose knowledge counts? In attempting to answer these questions, we should be careful to include a disability studies perspective. If disability studies is left out of these conversations, the field of STS isn't counting the voices of disabled people, nor is it utilizing some of the critiques that come from disability scholars. It is my hope that those of us working at these intersections can generate more curiosity about disability studies, awareness about accessibility issues in being able to share that knowledge, and further cross-pollinate these fields of study.

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