

OPPORTUNITIES FOR ACTIVISM WITH THE RIGHT TO SCIENCE

By Erica Lessem

Interview with Human Rights Expert Gisa Dang

What do you see as the relationship between human rights and activism, and how can a human rights frame bolster activism?



Human rights and activism are closely intertwined. Having a human rights framework, and accompanying human rights mechanisms through the United Nations, enables activism that might not have otherwise been possible. For example, in countries that have rather oppressive systems, a human rights

framework enables people to access advocacy channels globally that they might not have domestically. This acts as a loop: people who might not be able to march up to their government can appeal to global standards and mechanisms, which then may bring action that benefits the activists' home country.

A human rights framework is about uniting—also a key aspect of activism. It is uniting first because human rights are universal. Second, because a human rights framework gives a common language to issues activists encounter around the world. This specific language allows framing an individual experience as part of a systematic issue. It enables an individual or community to move from understanding a specific plight as happenstance, to seeing it as a systemic issue and doing something about it.

Moving to the right to science in particular, what dimension do you think the right to science adds to health and social justice activism?

On a very basic level, the right to science says that governments have to make sure everyone can enjoy the benefits of scientific progress and its applications. States have to develop, diffuse, and conserve science. This identification of a state role in ensuring that certain things that support science, and therefore health, happen, is an additional tool for activism. For example, where treatment doesn't exist, and where research or financing to find it doesn't exist, the government needs to find ways to make the funds available and allocate health budget to make evidence-based interventions available once developed.

How would you define participation in relation to the right to science? What does nothing about us, without us look like under a right to science lens?

There are at least two layers here, and I say at *least* because we're still at the beginning of understanding and applying the right to science. At the basic level, participation means scientists need to be able to *do* science. They need to have the means, methods, and tools of science, the freedom to conduct research, the means of knowledge, access to data. At the same time, activists and affected communities need to have a voice in *doing* science—the process *and* the decision-making. If we look at how the AIDS movement evolved, understanding the science gave the movement a lot of power. Even though back then people were not talking about the right to science, the fact that activists were able to gain and use this knowledge in negotiating with policymakers reflects the right to science and what it stands for. In fact, the text of the General Comment No. 25 on the right to science, just published this April, elevates participation of anyone as a core tenant of the right. It makes clear that participation in all facets of scientific inquiry is not limited to only one group of people, and in fact obligates states to make participation by anyone possible.

You've already worked with TAG on a fair amount of health advocacy and treatment literacy using a right to science angle. How do you see this work changing or evolving, in light of the general comment the United Nations Committee on Economic, Social, and Cultural Rights (CESCR) recently issued?¹

A general comment is an extensive analysis of a specific right within an international covenant. For example, because we have a general comment on the right to health, accessibility, affordability, acceptability, and quality (AAAQ) are accepted as the four important pillars of the right to health. Till now, we didn't have a similarly accepted interpretation of the right to science. Now that we have an authoritative analysis of the dimensions of the right to science, we know what obligations states as duty bearers have. We now have fairly clear standards against which each country's progress on right to science implementation will be measured by CESCR in their reporting. And we as activists have additional authority to make our arguments, e.g., public funding should lead to publicly available goods, which is mentioned in the GC. Now, we'll be able to move away from rather lonely desk work to activism and organizing. For example, we can create educational materials like toolkits, guides, and workshops, so that people can better understand the right and how it applies to them, so they can start actively engaging and utilizing the right in their activism. It's a coming-to-life process.

Do you have any concerns about how the right might be interpreted, in ways that could limit knowledge sharing or access?

I always have concerns about how human rights might be interpreted because we have to understand that just because a right exists doesn't mean that it is implemented in reality. With development and diffusion being part of the right to science, we have to look at who owns the knowledge and who owns the process of doing science. It is very exciting that the GC, for example, recognizes Indigenous People's ownership of their knowledge, land, and moral and material interests, including collective authorship. The GC also talks about IP, public funding resulting in public goods. However, the GC language is also one of "could" and "should". It is not a prescriptive "you must do this"- type of document. And while rights are interconnected and interdependent, they are not always interpreted as such; some countries interpret the right

to development, for example, as meaning they can infringe on other rights to realize that right. This is why it is important that the GC reminds states that if they need to limit the right, limitations have to be in accordance with law and must still respect the core obligations of the right. Use of science and technology can also be restricted to protect the safety of people involved, those using and subject to research or new technology. The GC suggests, for example, Human Rights Impact Assessments as one way to safeguard individual's dignity, as well as consent.

Legal challenges have been an important tactic in human rights-based activism. Could the right to science start to underpin legal challenges?

I strongly believe that activists are going to seize on it as an additional tool for their legal advocacy. The Optional Protocol to the International Covenant on Economic, Social, and Cultural Rights (ICESCR, which enshrines the right to enjoy the benefits of science and its applications) allows an individual to submit claims to the CESCR on any of these rights mentioned in the ICESCR if that individual has exhausted domestic measures to adjudicate this right. Now that we have clear core obligations, that will become an easier option.

I was curious if right to science had been used in legal advocacy, and I did find one case that cites right to science in both state and international law. In 1999, people living with HIV in Venezuela brought a case to the Constitutional Court² about the failure of the ministry of health to provide triple-drug therapy. The case mentioned the right to science because this right is part of the Venezuelan constitution. When I was working on [Universal Periodic Review submissions](#) for TAG, we found that the right to science is mentioned already in some regional human rights treaties as well as some constitutions and domestic legislation, e.g., Mexico has legislation that includes right to science.³ I think we'll see an increase in domestic cases, and once we have the normative content, we can then build the tools and the strategies to utilize the right to science.

Health activism often targets, in addition to state actors, non-state actors such as pharmaceutical companies, other product developers, and private philanthropies. How can the right to science be leveraged to influence and hold accountable these non-state actors?

Activism isn't a straight arrow approach. The challenge here is that governments are the ones responsible to uphold and implement human rights, but at the same time, there's a whole field of holding non-state actors that need to be accountable, including international businesses and conglomerates. Governments have a role to play here. They have the duty to ensure research happens and is made available, and it is secure for future use. States can give incentives as well as hold other actors accountable. While the GC doesn't go into much detail, it does mention the role of the state vis-à-vis multinationals, for example. Consumers can also have great influence on businesses, e.g., through movements to call for divesting assets from specific companies.

What about when governments themselves don't seem to care about human rights? The U.S., for example, has never even ratified important human rights conventions such as the ICESCR.

Human rights are universal. Even though a country may not have ratified the ICESCR, many of these rights, such as the right to science, already exist within the Universal Declaration of Human Rights. It's not as if not ratifying the ICESCR frees one of any responsibility of upholding these rights or that rights don't exist for people within a country's borders. It also doesn't mean that there isn't already national legislation

about any of these rights. On the other hand, the fact that laws are on the books doesn't mean that those rights are being implemented. This brings us to the one really important principle of participation which underpins all of it—you have to really understand your local context to find the best advocacy strategy. Depending on your audience, you can talk about and leverage human rights without saying *human rights*.

You have to think about who has the power to address what you need, who exerts power over them, and what information and strategies will get them to do what you need.

Endnotes

Gisa Dang is an experienced human rights activist who has been consulting with TAG for several years as we develop our right to science activism on tuberculosis, hepatitis C, and HIV. Previously, she worked with community groups in Asia to support their rights-based activism.

1. Committee on Economic, Social and Cultural Rights. General comment No. 25 (2020) on Science and economic, social and cultural rights Art. 15.1.b, 15.2, 15.3 and 15.4. United Nations. Geneva: 2020 Apr 7. <https://www.ohchr.org/Documents/HRBodies/GC7April2020.docx>.
2. ESCR-Net. Cruz del Valle Bermúdez y otros vs. MSAS s/amparo. Expediente N° 15.789. Sentencia N° 196. [ENG]. <https://www.escr-net.org/caselaw/2006/cruz-del-valle-bermudez-y-otros-vs-msas-samparo-expediente-ndeg-15789-sentencia-ndeg>.
3. Treatment Action Group. TB, Human Rights, and Universal Periodic Review. 2018. <https://www.treatmentactiongroup.org/letter/tb-human-rights-and-universal-periodic-review/>.